



*Patient-Centered Health Care Reform
Solutions*

By: National Patient Advocate Foundation

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Patient-Centered Health Care Reform Solutions

Executive Summary

NPAF's health care recommendations are grounded in more than 12 years of documentation across 300,000 closed patient cases reporting the concrete gaps and failures in our current health care delivery and financing systems. NPAF offers the following recommendations fully aware that achieving some would render others unnecessary or affect their implementation.

Goal: *Universal Access to Health Care Coverage*

- Eliminate pre-existing condition exclusions and waiting periods in all private and public insurance plans
- Support state reform efforts to improve access to health insurance coverage
- Expand Medicaid & SCHIP to cover all Americans below 300% of the federal poverty level; implement national and state strategies to increase enrollment and retention in Medicaid and SCHIP
- Allow individuals age 55 to 64 to buy into Medicare at the full actuarial cost
- Eliminate the two-year Medicare waiting period for people with disabilities
- Undertake a full scale audit of federal assistance programs focused on creating interdepartmental coordination, rationality and uniformity of safety net programs
- Provide tax incentives for small businesses so they can afford to offer health coverage and to individuals so they can afford to purchase health coverage
- Create a national program to allow consumers to purchase health insurance policies which they own and which are portable

Goal: *Ensure that Health Care Coverage is Affordable*

- Create a national reinsurance program (public and/or private) capping individual out-of-pocket spending while maintaining support for self-insured employers who provide wrap-around coverage
- Create a new entity or task HHS with the responsibility to establish and implement affordability standards based on recent research data on the impact of health care expenses on family budgets in combination with the IRS standard for medical expense deductions
- Create a program covering individuals with catastrophic medical needs to help stabilize and lower premiums; defined as spending more than 10% of annual income on medical expenses
- Establish a federal high-risk pool or a grant program to subsidize state high-risk pools and ensure affordable premiums and cost-sharing
- Amend Medicare Part D to apply the exceptions process for tiered formulary drugs to specialty tier drugs and limit consumer out-of-pocket to 25 percent of the Medicare cost-sharing for specialty tier drugs
- Allow individuals to purchase health insurance over state lines to improve affordability; ensure that premiums are affordable and a standard and comprehensive set of health benefits are guaranteed

Goal: *Improve the Quality of Health Care and Health Care Coverage*

- Establish a national minimum standard set of benefits through a new entity modeled after features in the Federal Employee Health Benefits Program
- Provide financial incentives to physicians, clinics and hospitals in order to promote adoption and use of a national interoperable health information system with a comprehensive privacy and security framework.

- Promote adoption of personal health records for all people in America, particularly young children, people with chronic illnesses and those with mobile jobs
- Promote primary prevention, including health screenings, immunizations, smoking cessation programs, exercising, and healthy eating, through investing wisely in clinical and community prevention services and publicly and privately-sponsored programs
- Invest in research on the comparative clinical effectiveness of treatment options to improve the quality, safety and delivery of care, but not to limit access, deny treatment or reimbursement

Goal: *Attain a Fair and Equitable Health Care System*

- Reform current bankruptcy laws to allow debtors to file medical bankruptcy
- Cap the interest rates that hospitals and credit card companies can charge for medical debt at prime plus 1 percent
- Require hospitals to charge uninsured patients with incomes less than 250 percent of the federal poverty level the average private insurer's negotiated rate
- Require insurers to cover emergency services rendered at a network facility by an out-of-network provider at no greater cost to the insured than services rendered by an in-network provider
- Develop and implement an education program in collaboration with the Centers for Medicare & Medicaid Services (CMS), employers, and insurers to send print materials to Medicare beneficiaries explaining the Medicare Secondary Payer (MSP) rules in easy-to-understand language

Goal: *Make Health Coverage Portable*

- Create a national program to allow consumers to purchase health insurance policies which they own and which are portable
- Enhance portability by eliminating pre-existing condition discrimination when individuals move or change health insurance plans

Patient-Centered Health Care Reform Solutions

Today in America, lack of access to health care is more deadly than illness. Forty five million people are uninsured and twenty five million are under-insured, resulting in twenty three percent of our population driving up the costs of health care for the remaining sixty-seven percent of insured people in America. Sixteen percent of the Gross Domestic Product of our country is now directed to health care costs, with the costs at the state level often exceeding the dollars required for education programs. Our nation is in a crisis with the Medicare Hospital Insurance Trust Fund slated to be bankrupt in 2019, Medicaid programs stripping services and beneficiaries from their rolls routinely and hospitals and clinics posting signs that they will no longer treat Medicare patients. Universally, there is consensus that our nation must turn its intellectual pursuits to finding practical, affordable solutions to these issues to assure the nation's financial stability while improving our population's health and wellness.

Representing the voices of more than twenty one million people in the United States who since 1996 have sought information or direct mediation and arbitration services through the professional case management staff of our companion organization, Patient Advocate Foundation, National Patient Advocate Foundation herein proffers national solutions for consideration during our nation's health care reform dialogues. These solutions have been shaped by human suffering and documented across more than 240 primary fields of data for twelve years spanning more than 350,000 cases of people with chronic, debilitating and life-threatening illnesses facing concrete obstacles to accessing health care in the U.S. Our professional experience and data universally uphold a vision of health care in America in which all people have access to health care supported by a system of reimbursement for preventive, diagnostic, therapeutic and maintenance services that offer quality and affordability.

Further, NPAF proposes a vision that embraces both government and private sector financing of health care coverage with subsidies for those without adequate resources and tax incentives for individuals and small businesses. Such provisions will help establish a health care system which promotes and achieves universal access to health coverage in America.

NPAF proposes that Americans must have a choice of their own health insurance policy, providers, treatment, costs, quality, site of care and protocol and that choice must include the choice to own their own policy that is affordable and provides security for reimbursement for standard services required to maintain a healthy life. Affordability standards should be established using recent data from the Center for Studying Health System Change on the impact of health care expenses on family budgets in combination with the current IRS standard for eligible medical expense deductions; currently set at 7.5% of gross annual household income. Additionally, NPAF proposes that catastrophic expenses would be covered through secondary reinsurance programs delivered through government and/or private sector programs. These programs would provide incentives to insurers to participate through a prescriptive process of national enrollment of all Americans into health insurance thus assuring universal participation while limiting risks for insurers and driving costs down for consumers.

Public participation must be initiated through national educational measures to inform 300 million people in America of their choices, costs, benefits and risks presented with simple, comprehensible language in an easy-to-understand format. Consumers must be empowered to make informed

decisions, and that empowerment will be improved through personal ownership of their health care plans. NPAF has a vision of individual ownership of health plans from birth to death allowing for portability, control of benefits and costs through personal choice within a national marketplace that is managing fundamental requirements for health plan benefits that are affordable and patient-centric. Consumers will make good choices when they are well-informed. Frequently today, consumers do not know that their employers define their benefits and because they are removed from the negotiations of both costs and benefits, they are uninformed about either. Unfortunately, individuals' costs are typically defined at the time of intersection between the patient and health care delivery system as is the comprehensive range of benefits, caps, co-payments, co-insurances and deductibles that are typically defined in generic terms in plan summary language at the time of enrollment.

NPAF proposes a vision in which quality health care eliminates the majority of medical errors, includes use of health information technology, electronic medical records, electronic health records and personal health records to reduce redundancies in tests, medications, protocols, provide reminders to enhance compliance to treatment, and improves safety in the health care delivery system while reducing costs. Both the Institute of Medicine and RAND Corporation have produced studies in 2004 and 2005 that cite only 55% of the time do patients get correct care resulting in 45% percent of the time patients receive incorrect care for their diagnosis.

National Patient Advocate Foundation strongly supports a national solution aimed at expanding access to health coverage while at the same time, implementing policies that will help reign in costs and spending without jeopardizing patient access to care. Health care reform must transform our health care system to reward quality, control costs, incent personal accountability and to insure that all people in America have adequate resources to purchase affordable health insurance products with quality coverage and benefits.

NPAF offers these numerous recommendations fully aware that achieving some would render others unnecessary or affect their implementation.

The vision described herein is further defined in the attached one page Executive Summary and rationalized in our Pillars of Health Care Reform Solutions that provide a research rationale for solutions proposed inclusive of operational recommendations. The proposed solutions are based on the fundamental belief that a responsible health care system is based upon the following principles:

- Universal Access
- Affordable Health Care
- Quality Care and Quality Coverage
- Fair and Equitable Health Care
- Portability

The decisions we make as we reform health care today will define our people's journey to wellness tomorrow.

Universal Access

Every American needs access to health coverage. NPAF supports a multi-faceted health care system that includes and supports the role of individuals and other stakeholders including public, private and non-profit stakeholders. Approximately 133 million Americans, or 45% of the population, have at least one chronic disease.¹ All of these individuals are at risk of facing health insurance discrimination due to their health status. 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. Those with chronic, debilitating diseases, even if preventable, should not be denied insurance coverage when they need it most due to pre-existing conditions.

Solution 1: Eliminate pre-existing condition exclusions and waiting periods for all group plans (including self-insured plans), private individual market policies, and state high-risk pools.

State reform efforts can serve as models to improve access to health insurance coverage. The federal government should look to these models in seeking to provide universal access to care, and it should encourage states to experiment with reform efforts with federal assistance. In 2006, Massachusetts enacted comprehensive health care reform requiring all residents to obtain health insurance coverage. Under the law, low-income residents are provided free or subsidized health coverage and employers are required to either provide coverage to their employees or pay an assessment to the state.² Two years later, an additional 439,000 residents are insured.³ Other states, including Vermont, Delaware and Florida, have adopted or are exploring creative reforms to expand access and improve affordability of health coverage.

Solution 2: Support state reform efforts to improve access to health insurance coverage.

Expanded access to health care coverage is also essential for low-income individuals and families. Seventy percent of uninsured children are eligible for low-cost or free health coverage through Medicaid or SCHIP but are not currently enrolled.⁴ All those currently eligible should be enrolled and the programs should be expanded to reach all those whose economic status places them at risk of not having affordable insurance.

Improving the development of outreach efforts to promote SCHIP enrollment is also a critical element to reducing the number of uninsured children. NPAF supports national and state strategies to further develop outreach methods that link together schools, community-based organizations, health care providers and private business groups to reach eligible but un-enrolled family populations and retain existing enrollees.

¹ Wu, S. Green, A. Projection of Chronic Illness Prevalence and Cost Inflation, RAND Corporation, October 2000.

² “Massachusetts Health Care Reform Plan – An Update.” Kaiser Commission on Medicaid and the Uninsured, June 2007.

³ K Lazar. “439,000 More Get Health Coverage.” Boston Globe, August 2008.

⁴ Dubay L., J Holahan, A Cook. “The Uninsured and the Affordability of Health Insurance Coverage.” *Health Affairs*. November, 2006.

Solution 3: Expand Medicaid and SCHIP to provide health coverage to qualified low-income children and families at or below 300% of the federal poverty level; implement national and state strategies to increase enrollment and retention in Medicaid and SCHIP.

Expanded insurance options are also critical for the population between 55 and 64 because age and pre-existing conditions contribute to expensive premiums and coverage gaps for this age group. In 2007, 10.8 percent⁵ of those currently uninsured were between the ages of 55 and 64. Providing affordable options for this demographic could also help our country reach universal access to care.

Solution 4: Allow individuals between 55 and 64 years old to buy into Medicare at the full actuarial cost or to become part of a national framework of health insurance options. The national framework shall not be designed to discourage the retention of employees' current health care coverage.

Nearly 7 million Americans under the age of 65 qualify for Medicare because they have severe and permanent disability.⁶ Unfortunately, our current system requires these individuals to wait two years after they are deemed eligible for Social Security Disability Insurance to receive Medicare coverage. Since almost 44% of PAF Medicare cases involve disabled individuals, case managers regularly assist patients stuck in the 24 month waiting period who are literally struggling to survive because they have no or limited health coverage.

Solution 5: Eliminate the two-year Medicare waiting period for people with disabilities.

PAF encounters patients every day who are caught in the maze of confusing and conflicting federal/state eligibility requirements further complicated by poorly managed state social service offices, the lack of well trained counselors and of clear patient friendly information related to eligibility criteria and sustained access to SSI, SSDI and Medicaid. Better coordination of federal assistance programs, including uniform eligibility requirements could help to streamline and make more efficient our health care system.

Solution 6: Implement a full scale audit of federal assistance programs specifically focused on creating interdepartmental coordination, rationality and uniformity of safety net program eligibility criteria and requirements. As part of this audit, simplify the Medicaid application to one page; base qualification on income status only. Make spend down available for applicants diagnosed with catastrophic illness or accident immediately. And finally, assure qualification in one program does not eliminate qualifications for other programs.

Health benefit costs are higher for small than large businesses. Few small employers have the specialized staff or resources to shop for and negotiate affordable premiums for their workers. In small firms one illness or injury must be shared across a small number of workers. For these reasons, fewer small businesses offer coverage in the first place. And when health care costs encroach on profits needed for sustainability, small businesses often curb or cut those expenses;

⁵ March Current Population Survey. Employee Benefit Research Institute. 2007.

⁶ R Hayes, D Beebe, and H Kreamer. "Too Sick to Work, Too Soon for Medicare: The Human Cost of the Two-Year Medicare Waiting Period for Americans with Disabilities." Medicare Rights Center, April 2007.

therefore it is not surprising that fewer than half (45 percent) of small businesses with fewer than 10 workers provided health insurance in 2007.⁷

Of all the workers in the U.S., the greatest number of uninsured is in firms with 25 or fewer employees (33 percent). Firms that employ 99 or fewer people account for nearly 50 percent of the uninsured workforce, but only one-third of the entire workforce.⁸ Since small business, defined as firms with fewer than 500 workers, account for approximately fifty percent of jobs in America⁹, tax incentives and health insurance plans designed to meet the needs of the small employer market would help bring insurance coverage to a significant portion of the currently uninsured.

Solution 7: Provide tax incentives for individuals and small businesses to make health insurance coverage affordable for small employers and individuals. Also design public/private funded group plans created specifically for small employers (under 50 employees) to give them more affordable insurance products to offer to their employees. This could also provide a vehicle for insurability for uninsured children.

Today in America, lack of access to health care is more deadly than illness. Forty five million people are uninsured and twenty five million are under-insured. This population of patients, representing twenty three percent of all Americans, is unintentionally but directly driving up the costs of health care for the remaining sixty seven percent of insured people in America because when they are in crisis and cannot pay for medical assistance, the burden falls on hospitals, doctors and the government. Billions of dollars in this kind of care, referred to as “uncompensated care” drives up premiums and costs for everyone. National Patient Advocate Foundation strongly supports a national solution aimed at expanding access to health care coverage. Americans must have choice in their health care and that choice must include the choice to own their own health care insurance policy. NPAF has a vision of individual ownership of health plans from birth to death allowing for portability.

Solution 8: Create a national program to allow consumers to purchase health insurance policies which they own and which are portable.

Affordable Health Care

A growing number of individuals and families are finding that they cannot afford health coverage due to rising premiums, deductibles, co-pays and coinsurance obligations in combination with accelerated use of caps on specific services, caps annually on specific disease benefits, and caps on lifetime benefits. Coverage should be available that is affordable for individuals, families, businesses and government.

As costs continue to shift to individuals and families, more Americans find themselves unable to afford coverage. In 2007, the average annual premiums for an employer health plan covering a family of four was \$12,106; the cost for single coverage was \$4,479.¹⁰ Since the late 1990s,

⁷ Kaiser HRET Employer Health Benefits Survey 2007

⁸ Health Insurance Coverage in America 2006 Kaiser

⁹ U.S. Department of Commerce, Bureau of the Census. September 2008.

¹⁰ Employer Health Benefits: 2007 Annual Survey. The Henry J. Kaiser Family Foundation and Health Research and Educational Trust, September 2007.

accelerated growth in health care spending has translated into increased burdens on family budgets. In fact, 18 percent of middle class insured families (with incomes above 200 percent of the federal poverty level or \$28,400 for a family of 4) carry a high financial burden for health care, defined as spending more than 10 percent of family income on health care.¹¹ When premium costs are added into the equation, even more families are devoting a substantial share of resources to health care expenses. Families struggling with high out-of-pocket (OOP) expenses are more likely than other families to report difficulties in obtaining needed care, and often have trouble paying their bills—increasing the possibility that they may face debt or bankruptcy or drop coverage altogether.¹²

This escalating OOP cost shift to patients is a leading contributor to medical debt and health related financial strife for Americans. In fact in 2007, 70% of NPAF callers reported that debt crisis was their first concern, compared to 28% in 2004 and 38% in 2005 and 2006. A recent report by The Commonwealth Fund found that 45 million non-elderly individuals live in families that carry a high financial burden for health care, defined as spending more than 10 percent of family income on health care.¹³ Individuals with private insurance are not the only patients struggling with medical debt, 15% of individuals in public insurance programs spend more than 10% of family income on health care.¹⁴ NPAF strongly advocates for health care reform measures that limit individual annual health care spending.

To assist patients with high out-of-pocket health expenditures, a national reinsurance program could serve as a backstop to the current insurance market by shoring up existing coverage limits. The program would be modeled on existing state programs for employers and insurers but with an additional component targeted at individuals. The reinsurance models can be federally supported or supported with a combination of public and private financing.

Solution 1: Create a national reinsurance program capping individual OOP spending while maintaining support for self-insured employers to provide wrap-around reinsurance coverage.

In addition, affordability standards need to be established in order to cap the health related expenses with which individuals and families are overburdened. The Center for Studying Health System Change released a report in December 2008, “Living on the Edge: Health Care Expenses Strain Family Budgets,”¹⁵ which illustrates the financial pressure many American families are under due to increasing medical bills. The purpose of the report was to identify the level of out-of-pocket medical expenses that result in a large number of families experiencing financial difficulties with medical bills in order to assist policy makers in developing affordability standards for out-of-pocket medical spending. Of the 14,500 people surveyed, half of those with medical bill problems spent 2.5 percent or less of their family income on out-of-pocket medical expenses, and more than two-

¹¹ Kaiser Family Foundation, “Health Care Affordability and the Uninsured,” Slide 10 in the Chartpack accompanying the testimony of Diane Rowland before the House Ways and Means Committee, April 15, 2008, available at <http://slides.kff.org/results.aspx?view=slides&detail=19>.

¹² M Merlis, D Gould, and B Mahato. “Rising Out-of-Pocket Spending for Medical Care: A Growing Strain on Family Budgets.” The Commonwealth Fund, February 2006.

¹³ Banthin J, Cunningham P, & Bernard D. Financial Burden of Health Care, 2001-2004. The Commonwealth Fund., January 2008.

¹⁴ Ku L & Broaddus M. Public and Private Health Insurance: Stacking Up the Costs. Health Affairs, June 2008.

¹⁵ P Cunningham, C Miller and A Cassil. “Living on the Edge: Health Care Expenses Strain Family Budgets.” Center for Studying Health System Change, December 2008.

thirds spent 5 percent or less. This report clearly identifies the serious problem health related expenditures pose for individuals with families. While affordability standards may need to be adjusted slightly depending on economic status, using the findings from this report as well as the IRS standard for medical expense deductions is a good starting point to develop affordability standards. The current IRS standard is 7.5% of annual household income.

Solution 2: The Department of Health and Human Services or a new entity should establish and implement affordability standards based on recent research data on the impact of health care expenses on family budgets in combination with the IRS standard for medical expense deductions.

A new program should be established to cover those with catastrophic medical needs to help stabilize and lower premiums; individuals with medical expenses exceeding 10% of gross annual income have reached catastrophic medical needs. Operationally, this proposal would be modeled after the Medicare End-Stage Renal Disease (ESRD) Program.

Solution 3: Establish a new program covering individuals with catastrophic medical needs to help stabilize and lower premiums. This new program would be activated once the patient's medical expenses exceed 10% of gross annual income.

Currently, only 34 states operate high-risk pools and nationally, high-risk pools only insure 207,000 patients.¹⁶ More must be done to assure that all states have high-risk pools, or alternatively, a federal high-risk pool should be created to assure that individuals with high medical costs have access to insurance coverage. More must also be done to assure that the coverage provided by high-risk pools is adequate and affordable.

Solution 4: Establish a federal grant program to subsidize state high risk pools or a separate federal high risk pool (modeled after state programs but with adequate funding to ensure affordability and access).

In 2007, 31% of PAF cases sought co-payment relief assistance. PAF provides co-payment relief to patients across the country who cannot afford their prescription drug co-pays; however, the demand for co-pay assistance has grown tremendously over the last several years as prescription drugs prices increase and patients are responsible for a greater portion of the drug's cost.

Solution 5: Amend Medicare Part D to apply the exceptions process for tiered formulary drugs to specialty tier drugs and limit to 25 percent the Medicare cost-sharing for specialty tier drugs.

NPAF supports allowing consumers to purchase health insurance across state lines, as long as affordable premiums and a standard and comprehensive set of health benefits are guaranteed. NPAF is concerned about this practice because research conducted by the New America Foundation in October 2008 found that while selling health insurance across state lines may result in lower premiums and health costs for the young and healthy, it would increase premiums and decrease benefits for sick individuals and even for individuals with minor conditions. Any proposal to allow

¹⁶ The Henry J. Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured, *Key Facts: The Uninsured and Their Access to Health Care*, October 2007.

the purchase of health insurance across state lines should include provisions to ensure affordable premiums and a standard and comprehensive set of health benefits.

Solution 6: Allow individuals to purchase health insurance over state lines as long as affordable premiums and a standard and comprehensive set of health benefits are guaranteed.

Quality of Care and Coverage

Our current system proves that obtaining affordable health care coverage does not guarantee the quality of that coverage or the quality of the care. NPAF supports the premise that every American should have timely access to quality coverage, including a minimum standard set of benefits void of excessive caps and out-of-pocket requirements. As well, NPAF supports the premise that every American should have timely access to quality care. Care should be consistent with prudent layperson standards. The standard considers whether the prudent layperson could reasonably expect the absence of immediate medical attention to result in placing the health of such person or others in serious jeopardy, serious impairment to such person's bodily functions, serious dysfunction of any bodily organ or part of such person, or serious disfigurement of such person.¹⁷ The health care system should incent quality and promote transparency to encourage patients to be better purchasers of health care.

PAF routinely hears from patients that are unable to access necessary health care services because their health plan imposes caps based on patient lifetime, disease (e.g. cancer) or services (e.g. prescription drugs) In fact, almost 16% of patients contacting PAF in 2007 reporting access to pharmaceutical issues said they had exceeded their benefit maximum. One example is a 50-year old North Carolina man who contacted PAF after being diagnosed with pancreatic cancer. He soon discovered his insurance capped his maximum benefit on prescription drugs at \$1,000 per year and capped his oncology benefits at \$10,000 per year.

Another PAF patient employed by one of the largest fast-food restaurant chains in the country discovered his annual cap on oncology benefits in 2008 was \$30,000; thus rendering him essentially uninsured. Physicians, hospitals and community clinics declined service knowing he did not have adequate health insurance, personal resources and he was ineligible for public, ecumenical or social service programs. Unfortunately for this patient, he assumed the health coverage offered to him by his employer was quality health coverage and covered his cancer care. For individuals with chronic, debilitating, or life-threatening conditions, these bare bones benefits limit or deny health care access while increasing financial distress.

Solution 1: Establish a federal minimum standard set of benefits modeled after the FEHBP plan provisions for all individual, employer-sponsored and government entitlement health plans. In addition, NPAF proposes requiring group and individual health insurance plans to cover approved cancer clinical trials including coverage for routine patient costs associated with clinical trials. Such coverage is consistent with the coverage provided to Medicare beneficiaries.

¹⁷ Health Bureau of the New York Insurance Department, January 2002.

NPAF supports grants to providers to encourage the early implementation of health information technology systems which could ease the financial burden of adopting these systems. NPAF supports the work of AHIC 2.0, the American Health Information Community, a federally-chartered advisory committee which provides recommendations to the Department of Health and Human Services on how to make health records digital and interoperable and assure that the privacy and security of those records are protected. NPAF believes that the first issue to be addressed must be privacy and security standards for patients that should include federal HIPAA protections in place for individuals.

Solution 2: Establish a federally funded interoperable health information system with a comprehensive privacy and security framework that sets clear parameters for access, use and disclosure of personal health information for all entities in e-health.

In addition, patients should have access to their personal health records (PHRs). Personal health records are products that can collect, collate, and present the comprehensive data needed by engaged, activated individuals. PHRs will ensure improved access to usable electronic health information and will help improve health literacy, patient-provider communication, care coordination, and overall quality of care. Health care organizations should provide consumers with their personal health information in a useable, standardized electronic format. Informing patients about the benefits of PHRs is critical, and outreach to consumers should be conducted by community clinics, schools, churches, state entities, employers, providers and insurers.

Solution 3: Promote adoption of personal health records (PHRs) for all people in America, particularly young children, people with chronic illness and those with mobile jobs.

The treatment of chronic illnesses such as diabetes, cancer, obesity, and heart disease accounts for 75 percent of U.S. health care spending. In order to improve our nation's health and spend our resources more effectively, we must put greater emphasis on efforts to keep people healthy. We must focus on prevention, as opposed to only treating individuals when they become ill. A recent study¹⁸ found that 58.6 percent of adult respondents have not adopted behaviors, such as health screenings, immunizations, good dieting and exercise practices, to support their health, and 14.6 percent lack the basic knowledge to manage their health. This lack of attention to prevention can be linked to low prevention coverage in employer plans. According to a Robert Wood Johnson Foundation report examining employer-sponsored health insurance plans, only slightly more 50 percent of plans covered physical examinations, immunizations and screenings while only some 20 percent of plans covered lifestyle modification services such as tobacco cessation interventions (e.g., counseling and/or medication), and 18 percent covered screening, counseling and medical therapy for weight loss management and alcohol problem prevention.¹⁹

Solution 4: Promote primary prevention by requiring every health insurance policy to include preventive services, by investing wisely in clinical and community prevention services and publicly and privately-sponsored programs, and by providing incentives for beneficiaries to engage in primary preventive measures like exercising, healthy eating and

¹⁸Hibbard J & Cunningham P. How Engaged Are Consumers in Their Health and Health Care, and Why Does it Matter. Center for Studying Health System Change. October 2008. <http://www.hschange.com/CONTENT/1019/>

¹⁹ Partnership for Prevention/Mercer Human Resource Consulting Survey of Employer-Sponsored Health Plans, June 2007.

smoking cessation programs. Such efforts will reduce health care costs and spending such as reduced premiums.

NPAF supports establishing a new entity, which obtains its funds from both federal appropriations and pre-established contributions from sources within the private sector, to conduct research on the comparative clinical effectiveness of various treatment options for those with chronic and debilitating diseases. This entity would coordinate research priorities, while allowing academic institutions and research centers throughout the country to perform reviews on a set of previously determined conditions and interventions. The steering organization of the research entity should consist of all relevant stakeholders, including patient and consumer groups, and should help set the research agenda, develop study methodology, and disseminate findings. The earliest studies should be selected and prioritized based on conditions with the greatest impact on overall national health. Comparative effectiveness research should be performed in order to improve the quality, safety and delivery of care not to limit access, deny treatment or reimbursement. Research findings should not over-look subpopulations (orphan diseases or ethnic populations) that may benefit from a particular treatment or neglect the needs of patients for whom the findings are not necessarily supportive which may include patients with multiple co-morbid, complex conditions. Special attention and consideration should also be given to cancer due to the heterogeneity of cancers. Two patients who have superficially similar disease and who have the same recommended treatment can have very different outcomes.

The information gained through such research could be used to educate individuals on the options available, and to better equip them for the decisions they must make with their physicians regarding the best course of action in treatment.

Solution 5: Invest in research on the comparative clinical effectiveness (not cost-effectiveness) of the multiple treatment options for those with chronic, debilitating and life-threatening conditions.

Fair & Equitable Health Care

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 and provide necessary coverage to those who need it when they need it.

A recent report by The Commonwealth Fund, found that nearly 41% of adults age 19 to 64 (approximately 70 million people) experienced problems paying their medical bills in the last 12 months or were in the process of paying off medical debt accrued over the last three years. Study participants also said they were forced to make significant life changes in order to pay such bills, or went without necessary care. In addition, it is estimated that more than one half of all bankruptcies are caused primarily by medical debt.²⁰

²⁰ Himmelstein, M., Warren, E., Thorne, D. and Woodhander, S., *Illness and Injury as Contributors to Bankruptcy*, Health Affairs, February 2005.

The bankruptcy law that went into effect October 2005 implements a “means test” requirement that will be used by the courts to determine eligibility for Chapter 7 or Chapter 13 bankruptcy.²¹ Means testing is an investigation into the financial well-being of a person. For individuals with medical debt, means testing may increase the level of financial distress they are already experiencing because the new bankruptcy rules will force many individuals to file Chapter 13 because the means test takes into consideration the person’s income. Under Chapter 13, debtors must pay back a significant portion of their debt within a short time period instead of having their debts excused under Chapter 7.²²

Solution 1: Reform current bankruptcy laws to allow debtors to file medical debt.

Patients are increasingly placing their medical expenses on credit cards whose high interest rates can skyrocket to 27.99 percent retroactively if a single payment is late or missed.²³ For patients who are struggling through intense health care treatments, it is easy to understand how a payment may accidentally be late or missed thus contributing to the patient’s financial and personal distress. Further straining patients are the prices the uninsured are charged for medical care. A 2007 study²⁴ found that uninsured patients and patients who pay for their medical care out-of-pocket are typically charged 2.5 times more for hospital care than those covered by an insurance policy and more than 3 times the allowable amount paid by Medicare.

Solution 2: Cap the interest rate that hospitals and credit card companies can charge for medical debt at the prime rate plus 1%.

Solution 3: Require hospitals to charge uninsured patients with incomes less than 250 percent of the federal poverty level the average private insurer’s negotiated rate.

Solution 4: Require insurance companies to cover emergency services rendered at a network facility by an out-of-network provider performing the services at a network facility, at no greater cost to the covered person than if the services were obtained from an in-network provider.

Medicare Secondary Payer (MSP) rules determine which plan, Medicare or a private plan, is the primary payer and which is secondary payer. For certain categories of people, Medicare is the secondary payer regardless of state law or plan provisions. These Federal requirements are found in Section 1862(b) of the Social Security Act. Patients regularly contact PAF after they have been informed that Medicare, not their employer or retiree health insurance, should have been the primary payer. In these circumstances, patients have opted out of Medicare Part B because they thought their employer or retiree insurance would cover their health care needs. These patients find themselves kicked out of their employer or retiree coverage when the mistake is discovered, and they are unable to enroll in Part B until the annual enrollment period which could be months away. Often this results in care that is delayed or foregone due to substantial financial burden. A

²¹ J Sahadi. “The New Bankruptcy Law and You.” CNNMoney.com, October 2005.

²² C Phelan. “The New Bankruptcy Law “Means Test” Explained in Plain English.” September 2005.

²³“Overdoes of Debt – Lenders Push Risky Credit for Everything from Cancer to Botox.” ConsumerReports.org, July 2008.

²⁴ Anderson, G.F. “From ‘Soak the Rich’ to ‘Soak the Poor’: Recent Trends in Hospital Pricing.” Health Affairs, May/June 2007.

clarification of these rules is needed to facilitate a more seamless coordination of benefits for patients.

Solution 5: Develop and implement an education program in collaboration with the Centers for Medicare & Medicaid Services (CMS), employers, and insurers to send print materials to Medicare beneficiaries explaining the Medicare Secondary Payer (MSP) rules in easy-to-understand language.

Portable

Americans must have choice in their health care and that choice must include the choice to own their own health care insurance policy. NPAF has a vision of individual ownership of health plans from birth to death allowing for portability.

Patients should be allowed to take their health coverage with them when they change jobs or move. Portable health insurance will allow for improved continuity of care and coordinated care because patients will not be forced to find new doctors who are part of their network every time they change jobs and health insurance policies.

Solution 1: Create a national program to allow consumers to purchase health insurance policies which they own and which are portable.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was designed to help ensure the availability and renewal of health insurance coverage for certain individuals; but significant gaps remain in the law – gaps through which individuals can fall due to a pre-existing condition. Portability as a concept only works if all consumers are guaranteed that their pre-existing conditions are covered.

Solution 2: Enhance portability by eliminating pre-existing condition discrimination when individuals move or change health insurance plans

