

putting patients first[®]

PRINCIPLES FOR PATIENT-FOCUSED HEALTH CARE REFORM



OUR MEMBERS

Voluntary Health Agencies

Alpha-1 Foundation
The ALS Association
Alzheimer's Association
American Autoimmune Related Diseases Association
American Cancer Society
American Diabetes Association
American Heart Association, Inc.
American Kidney Fund
American Liver Foundation
Arthritis Foundation
Asthma and Allergy Foundation of America
Autism Society of America
Barth Syndrome Foundation
Breast Cancer Network of Strength
CHADD
Easter Seals
Epilepsy Foundation
Huntington's Disease Society of America
Hydrocephalus Association
International Pemphigus & Pemphigoid Foundation
Interstitial Cystitis Association
The LAM Foundation
Lance Armstrong Foundation, Inc.
Lupus Foundation of America, Inc.
March of Dimes Foundation
Mental Health America
Mesothelioma Applied Research Foundation
Myasthenia Gravis Foundation of America, Inc.
National Alopecia Areata Foundation
National Down Syndrome Society
National Eczema Association for Science & Education
The National Foundation for Ectodermal Dysplasias
National Hemophilia Foundation
National Kidney Foundation
National Marfan Foundation
National Multiple Sclerosis Society
National Osteoporosis Foundation
National Psoriasis Foundation
Osteogenesis Imperfecta Foundation
The Paget Foundation

Parent Project Muscular Dystrophy
Prevent Blindness America
RESOLVE, The National Infertility Association
Sjögren's Syndrome Foundation
Spina Bifida Association
Spondylitis Association of America
Us TOO International, Inc.

Professional and Membership Associations

AcademyHealth
Advanced Medical Technology Association
Alpha-1 Association
American Academy of Hospice and Palliative Medicine
American Academy of Nursing
American Association for Respiratory Care
American Association on Health and Disability
American College of Cardiology
American Dietetic Association
American Institute for Medical and Biological Engineering
American Mental Health Counselors Association
America's Health Insurance Plans
Association of Air Medical Services
Association of American Medical Colleges
Biotechnology Industry Organization
Commissioned Officers Association of the
U.S. Public Health Service
Community Health Charities
Consumer Healthcare Products Association
Friends of Cancer Research
Friends of the National Institute of Dental
and Craniofacial Research
Interamerican College of Physicians and Surgeons
National Alliance for Eye and Vision Research
National Alliance for Hispanic Health
National Family Caregivers Association
National Pharmaceutical Council, Inc.
Partnership for Prevention
Pharmaceutical Research and Manufacturers of America
Society for Investigative Dermatology
WomenHeart

Nonprofit Organizations

CaringBridge
The Critical Path Institute
Guide Dog Foundation for the Blind, Inc.
Kanter Family Foundation
The Milken Institute/FasterCures
The Center for Accelerating Medical Solutions
Miracle Flights for Kids
The National Council on Aging
The National Health Museum

Business and Industry

Abbott
Amgen Inc.
AstraZeneca Pharmaceuticals
Bristol-Myers Squibb Company
Eli Lilly and Company
EMD Serono, Inc.
Endo Pharmaceuticals, Inc.
GE Healthcare
GlaxoSmithKline
Johnson & Johnson
Merck & Co., Inc.
Microsoft Corporation
Novartis Pharmaceuticals Corporation
Novo Nordisk Inc.
Pfizer Inc
Roche
sanofi-aventis
Takeda Pharmaceuticals North America, Inc.
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Associate Members

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The National Health Council is the only organization of its kind that brings together all segments of the health care community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 national health-related organizations, its core membership includes approximately 50 of the nation's leading patient advocacy groups. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device and biotechnology companies. The National Health Council brings together diverse stakeholders within the health community to work for health care that meets the personal needs and goals of people with chronic diseases and disabilities.

To learn more about the National Health Council, visit www.nationalhealthcouncil.org

putting patients first[®]

PRINCIPLES FOR PATIENT-FOCUSED HEALTH CARE REFORM

Millions of Americans wake up every morning facing the physical and mental challenges of chronic diseases and disabilities. It's the young mother anxiously watching and waiting for her child's first words only to be told he has autism, and the busy career woman who attributes her forgetfulness and sleepless nights to stress but really is experiencing the first symptoms of multiple sclerosis. It's the former school teacher who learns the only traveling he will do in retirement is to a local hospital for kidney dialysis. It's the wife whose heart breaks as she surrenders her husband diagnosed with Alzheimer's to the care of a nursing facility when she becomes too frail.

We all know someone—if not ourselves—who struggles to overcome the grip of chronic diseases and disabilities. While the health consequences are real, these individuals also face the often-times frustrating maze of the health care system and the financial burden of high premiums and out-of-pocket costs even with health insurance coverage. The toll can be devastating for their health and their family's financial well-being.

The National Health Council represents patient and other health-related organizations dedicated to putting the needs of patients first. That is what we do and that is what our health care system should always do.

We believe that the health care system can be both affordable and effective for everyone when it provides more coordinated care, improves patient outcomes that lower costs to society and keeps pace with biomedical innovation. Access, affordability, innovation and high quality care should be the benchmarks for health care in America.

Putting Patients First[®] means creating a modern health care system that saves lives, enhances our quality of life and saves us all money.



Create a modern health care system that saves lives, enhances our quality of life and saves us all money.

The touchstones for health care that work for all.

1. Cover Everyone
2. Curb Costs Responsibly
3. Abolish Exclusions for Pre-existing Conditions
4. Eliminate Lifetime Caps
5. Ensure Access to Long-Term and End-of-Life Care

1. Cover Everyone

Too many Americans lack health insurance or are underinsured, often with dire consequences ranging from crushing medical debt to skipping essential care to facing life-threatening conditions that could have been diagnosed and treated with proper access to care.

In 2007, the number of uninsured Americans was 45.6 million down from 47 million in 2006.¹ That's the good news. The bad news: this decline was driven by more people becoming eligible for government programs such as Medicare and Medicaid² and is still 20% higher than in 1999.³ The number of underinsured Americans in 2007 was 25 million, an increase of 60% since 2003.⁴

This situation results in tremendous costs to those who are uninsured, their families and society. A study by the American Cancer Society found that, for those cancers that can be detected early through screening and/or symptom assessment, uninsured Americans were two to three times more likely than those with private coverage to be diagnosed in Stage III or Stage IV rather than Stage I.⁵ *The Washington Post* noted that a 2006 study of 25 primary care private practices in the D.C. area found that in 1 in 4 encounters, physicians adjusted treatment based on a patient's insurance status. In some cases, doctors were also inflating the cost of insured patients' treatments to cover the costs of treating the uninsured.⁶ The deleterious effects to society of a large uninsured and underinsured population include the cost burdens of paying for uncompensated care and lost productivity in the workplace resulting in an impact on the overall economy.

Making health care available and affordable for all Americans is the foundation of a strong health care system. It must be the cornerstone of any proposed health care reform.

2. Curb Costs Responsibly

Health care reform discussions inevitably involve a focus on controlling costs. Proposals for reigning in costs range from enhanced use of health information technology to better care coordination. Whatever the suggested reform, it is imperative that

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consideration be given to the needs of patients, especially those with chronic conditions. Any plan that attempts to cut costs without taking into account the impact on patients is bound to have unintended negative consequences. While it is essential to seek maximum value for the nation's investment in health care, it must be done in a way that is patient-focused and produces improved outcomes, increased productivity and monetary savings.

High Costs Not Producing Better Health Outcomes

There is wide agreement across the political spectrum that America spends too much on health care without receiving commensurate value in terms of improved outcomes and healthier citizens. Health care spending, accounting for nearly 16% of gross domestic product (GDP) in 2008, is expected to grow to more than 22% of GDP by 2020 and will consume more than half of federal spending by 2050.⁷ U.S. health care spending averages \$7000 per person—double the figure in several other industrialized countries.⁸

Chronic conditions are responsible for much of this spending. At least 75% of the \$2 trillion spent on health care is due to chronic conditions.⁹ Sixty-five percent of health care spending goes toward treatment of people with two or more chronic conditions.¹⁰ More than \$277 billion is spent annually to treat just seven chronic conditions—cancer, diabetes, hypertension, stroke, heart disease, pulmonary conditions and mental disorders.¹¹

In spite of these huge expenditures, the U.S. does not experience better health outcomes than other nations that spend far less on health care. In 2000, the World Health Organization first ranked the health systems of 191 nations, with the United States coming in 37th.¹² The U.S. ranks 29th in infant mortality, 48th in life expectancy, and, in a ranking of 19 industrialized nations, 19th in preventable deaths.¹³ Researchers at Dartmouth estimate that up to 30% of health care spending, approximately \$700 billion, does not improve care or outcomes.¹⁴

Rising Costs a Burden to Individuals and Families

As efforts are undertaken to rein in health care spending and improve health outcomes, it is critically important to control costs in a way that does not put a greater financial burden on patients or deny them effective treatments.

Individuals have been forced to bear a greater financial burden as they spend more out of pocket on their medical care. Out-of-pocket costs have risen more than 25% over the last five years.¹⁵ In 2008, according to Hewitt Associates, an employee's contribution toward the premium on employer-sponsored coverage increased on average by 9.8% to \$1806, while Mercer found that the average annual deductible for employees covered under employer plans passed \$1000, a 17% increase over the previous year. Out-of-pocket costs average \$1707.¹⁶ In one survey, 41% of respondents said they had spent more than \$1000 out of pocket the previous year.¹⁷

Predictably, more Americans are having trouble paying their medical bills. The number of people struggling to pay medical bills increased by 14 million from 2003–2007, to a total of 57 million.¹⁸ Sixty percent of these people said their problems were the result of a family member's illness. Ultimately, many were forced to declare bankruptcy, with 2.2 million people being in families that had done so.¹⁹ Medical bills and/or accumulated debt have led to approximately 28 million Americans using



America spends too much on healthcare without receiving commensurate value.

up all savings, 21 million racking up large credit card debt, 21 million being unable to pay for basics such as food and rent, and 8 million taking out a mortgage against their home.²⁰

These financial burdens have impacted the ability of Americans to get the care they need. A survey by the Kaiser Family Foundation and CBS News found that, due to cost, 36% of respondents delayed medical care in the previous year, 31% did not have a test or treatment and 27% opted not to fill a prescription.²¹ In the U.S., the number of prescriptions filled in the first eight months of 2008 declined from the same period in 2007—the first decline in 10 years.²²

Comparative Effectiveness Studies Must Consider Patients

Comparative effectiveness research (CER) is defined by the Congressional Budget Office (CBO) as “a rigorous evaluation of the impact of different options that are available for treating a given medical condition for a particular set of patients.”²³ CER has been endorsed by policymakers as a way to control costs and improve quality, and the federal government has allocated funds to undertake such studies in an effort to achieve greater medical and economic value from the health care system.

It makes perfect sense that medical care should be based on evidence of the best, most effective treatments for patients with like diagnosis. However, creating a “one size fits all” mode of care could limit access to potential treatments for subsets of the population. The IOM gets to the heart of this potential problem: studying what works for a broad group of patients could lead to treatments being endorsed or discouraged based on data of the “average patient.”

CER must consider the clinical effectiveness of a particular treatment at the point of care, integrating clinical expertise with the best evidence and individual patients’ predicaments, rights, and preferences to support making the best health care decisions.²⁴ Care planning must take into consideration the patient’s unique personal circumstances, including the individual’s genetic, ethnic, religious, and socioeconomic status.

As personalized medicine is making clearer the different ways individuals and groups of individuals experience illness and respond to treatment, it would be nearly impossible to design clinical trials that are sufficiently broad in scope. For that reason, comprehensive comparative effectiveness research should examine the efficacy of a treatment under different circumstances.²⁵

The NHC strongly supports the thoughtful approach taken thus far to establish rigorous methodological standards to *conduct* comparative effectiveness research and would like to further efforts to ensure the merit of CER by supporting the creation of standards on the usefulness of the *results* of CER studies concerning various types of health care decisions.

Providers, patients, and the public must be able to trust that decisions based on CER are valid and appropriate. While the quality of the outcomes of CER are often discussed in terms of scientific rigor, a dimension of CER that has not yet been addressed is the usefulness of CER for decision making in real-world settings. Methodological standards provide guidance to researchers for how to produce high-quality research. In contrast, usefulness standards would help guide decision makers on the strength of

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the research, its place in the context of other existing evidence, and how the research may inform real-world decisions.

Such usefulness standards will help to ensure that CER fulfills its promise to improve health outcomes while simultaneously lowering costs by integrating the best evidence with individual patients' predicaments, rights, and preferences to support improved decision making at the point of care.

Strategies to Improve Outcomes and Reduce Costs

There are effective ways to reduce costs in the health care system, making it more efficient and better able to meet the needs of patients, providers, payers and other stakeholders. Key stakeholders have already implemented some strategies while others have been promoted by leading voices in the policy arena.

One area with the potential to reduce costs is addressed previously: covering the uninsured. The Institute of Medicine has estimated that covering the uninsured could result in \$130 billion annually in economic gains. A more recent study by the New America Foundation stated that \$204 billion could potentially be saved.²⁶

Across the political spectrum, discussion of health care reform has included certain common proposals to achieve cost-savings: adopt health care information technology (IT), improve efficiency, focus on prevention and utilize care coordination.

Adopt Health Information Technology

The U.S. has been comparatively slow to adopt greater use of health care IT. Approximately 25% of U.S. doctors have electronic health records, a rate far below the 90% seen in countries such as the U.K. and the Netherlands.²⁷ Few doctors, roughly 6%, prescribe medication electronically, despite the possibility of increasing efficiency and reducing or eliminating prescribing errors.²⁸ A recent examination of e-prescribing in Massachusetts found that, after a year, the result was "savings for consumers and insurers of \$845,000 per 100,000 patients."²⁹ It has been estimated that increased use of health IT throughout the health care system could result in savings of \$88 billion over 10 years.³⁰ The Rand Corporation projects greater savings, estimating that adoption of health IT by 90% of doctors and hospitals could potentially result in savings of \$80 billion per year.³¹

Improve Efficiency

The Commonwealth Fund's 2008 scorecard for U.S. health system performance defines an efficient health care system as one that "seeks to maximize health outcomes and quality for the resources spent and to enhance value over time." It then concludes, "performance on indicators of efficiency remains especially low" for the U.S. system.³² When patients see multiple physicians, as many with chronic conditions do, there is "poor communication and lack of clear accountability for a patient" that results in "medical errors, waste and duplication."³³

A survey of 1200 Americans found that one-third of respondents reported that "medical records or test results were not available during a scheduled visit or that tests were duplicated unnecessarily."³⁴ Forty percent found it very difficult to get needed care outside of office hours.³⁵ In addition, administrative costs rose dramatically between 2000 and 2006, increasing by 68% on a per capita basis—an amount that is 30–70%



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higher than in three other industrialized countries (Germany, the Netherlands, and Switzerland) where private insurance is common.³⁶

Correcting these and other examples of inefficiency could produce substantial savings for the U.S. health care system. Reducing administrative costs to levels seen in other countries with a large private insurance market would result in savings of \$51 billion annually.³⁷

Medical errors and adverse events are areas in which desperately needed improvements would produce substantial savings. Preventable medical errors are responsible for 50,000–100,000 deaths annually. Each year, there are more than 1.5 million preventable adverse drug reactions.³⁸ The Institute of Medicine in 2000 estimated that medical errors cost \$17–29 billion annually, in addition to lives lost or negatively impacted.³⁹ The Centers for Medicare and Medicaid Services will cease payment for “never events,” estimated to save roughly \$21 million per year but also likely to spur greater attention to reducing medical errors overall.⁴⁰ Increased use of health care IT would also be of great value in this effort, reducing the likelihood of treatment and prescription errors.

Utilize Care Coordination

Chronic care coordination, such as payment per episode of care rather than fee for service, could save Medicare \$229 billion over 10 years. Improving emphasis on primary care that provides care coordination and access to after-hours care could reduce costs to Medicare by \$194 billion over 10 years.⁴¹ Greater savings could be achieved if these programs were implemented in the private insurance market as well.

The importance of care coordination has increasingly been recognized in recent years. The Commonwealth Fund’s 2009 Report, *The Path to a High Performance U.S. Health System: A 2020 Vision and the Policies to Pave the Way*, included as one of its goals “accountable, accessible patient-focused and coordinated care.”⁴² The report further “envisions a health system that provides patients with personal sources of care who know their medical history, ensures timely access, helps coordinate care, and uses essential clinical data to provide the right care with an emphasis on health and disease prevention.”⁴³ Such policies, combined with other recommendations, could reduce the growth in health care spending by \$3 trillion by 2020 according to Fund estimates.⁴⁴

Care coordination has the potential to produce substantial benefits for patients and the health care system. Hewitt Associates found such integrated care delivery systems to be 22 percent more cost efficient than other systems.⁴⁵ The Centers for Medicare and Medicaid Services is funding a Medicare demonstration project in 14 communities to reduce elderly hospital readmissions, which increase annual Medicare costs by \$12 billion annually. The program features a health coach who works with the patient, with regular follow-up at scheduled intervals. The health coach helps the patient devise questions for the primary care physician and arranges a plan for patient self-care after leaving the hospital.⁴⁶

Focus on Prevention and Disease Management

Chronic conditions are widespread, accounting for 75% of total health care spending in the U.S. To address both the prevalence and costs of chronic conditions, it will be essential to adopt strategies that emphasize prevention and disease management to reduce the impact on individuals and the health care system. According to the World Health Organization, 80% of premature heart disease, stroke and type 2 diabetes as

Coordinated care enables doctors to discern which prevention measures and treatments are most effective, sparing the patient duplicative, unnecessary or even harmful care.



well as 40% of cancers could be prevented by regular physical activity, a healthy diet and not smoking.⁴⁷ A study funded by the Centers for Disease Control and Prevention and the Robert Wood Johnson Foundation found that community programs encouraging people to get more exercise were a sound investment. The programs reduced the number of new cases of heart disease, type 2 diabetes, breast cancer and colon cancer.⁴⁸

The Milken Institute reports that improved prevention and treatment of seven major chronic diseases would result in cumulative avoidable treatment costs of \$1.6 trillion by 2023.⁴⁹ The National Center for Quality Assurance calculated that improved care of diabetes could produce savings of \$1.3 billion or more annually in avoidable hospitals costs. Colorectal cancer screening and controlling high blood pressure could result in annual savings of more than \$284 billion and \$292 billion respectively.⁵⁰

Related to prevention and disease management is the idea of providing incentives for healthy behaviors. These could include participation in wellness programs, taking advantage of prevention services and programs, reconfiguring drug formularies to incentivize patient compliance with recommended treatment, getting regular screenings, and living a more active lifestyle. The Commonwealth Fund has calculated that implementation of such a benefit could net savings of \$19 billion over 10 years with an investment of \$2 billion by the federal government.⁵¹

Success Stories

Strategies are already being implemented by employers, providers and insurers, producing better health outcomes and improved savings.

- **Companies are offering their employees on-site clinics, wellness programs and reduced premiums and deductibles to improve employee health and lower costs.** Intel, Walt Disney and Toyota have opened on-site medical centers for employees. The sites are staffed by physicians and nurses and offer free or reduced-cost care, including annual physicals and blood pressure screenings. Pitney Bowes also offers an on-site clinic for employees, describing the clinic as a “long-term investment in employees.” The company states that for every dollar spent on the clinic, it gains a dollar in health care savings and another dollar in increased productivity. Pitney Bowes, Marriott and Toyota are among the companies that have eliminated co-pays on drugs for some chronic conditions. Employers are also offering incentives, such as reduced premiums or deductibles, for those who participate in wellness or disease management programs.⁵² The Business Roundtable found that 82% of its members offer disease management programs, 74% have smoking cessation programs and 85% have weight management programs.⁵³ Furthermore, the National Business Coalition on Health includes six coalitions with programs that offer diabetes medication with no co-pay and six that offer financial incentives to doctors who work with patients to control their diabetes.⁵⁴

- **Health systems are experimenting with new delivery models.** The Geisinger Health System in Pennsylvania began in late 2005 to implement programs to improve patient care, including management of chronic diseases, use of a personal health navigator to improve primary care, and redesigning treatment in



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acute care episodes. Key features included financial incentives aligned with quality care goals and patient engagement. Preliminary results have been encouraging. Two pilot sites using a personal health navigator reported first year results including a 20% reduction in hospital admissions and a 7% savings in medical costs. A program to improve management of diabetes also showed positive outcomes, with improvements in several benchmarks such as achieving target levels for blood glucose and blood pressure.⁵⁵

- **Hospitals are improving quality clinical care processes.** In an effort to promote high quality care and cost efficiency, Blue Cross Blue Shield in 2005 began awarding hospitals with the label “Blue Distinction” if they met certain benchmarks. A study of 24 hospitals found that hospital readmission rates after bypass surgery and angioplasty were lower by 26% and 37% respectively at Blue Distinction centers. Total costs for a 90-day episode of care were lower by 5% for bypass surgeries and 12% for angioplasties.⁵⁶
- **Insurers are reducing or eliminating co-pays on medication for chronic conditions.** Forward-thinking insurers are recognizing that reducing out of pocket costs for those with chronic conditions can improve treatment adherence and lower costs. From July through December 2008, Independence Blue Cross of Pennsylvania offered the Rx for Better Health Program, which eliminated co-pays on 75 medications used in the treatment of chronic conditions such as depression, heart disease, diabetes and high blood pressure. A program administrator noted that benefits extend beyond treatment adherence to a reduction in more serious medical problems and less worker absenteeism.⁵⁷ In November 2008, Cigna reduced the co-payment on Lipitor by half to encourage treatment compliance.⁵⁸

It is essential for all Americans to be able to obtain and retain affordable coverage regardless of pre-existing conditions.



These are just a few of the innovative reforms being implemented with the dual goals of generating long-term savings and ensuring that people with chronic conditions have access to effective care that enables them to live healthy and productive lives. Such programs demonstrate that patient-focused care is absolutely the most cost-effective reform strategy available.

3. Abolish Exclusions for Pre-existing Conditions

More and more Americans are challenged by chronic conditions—a total of 133 million people as of 2005.⁵⁹ Of that total, approximately 63 million Americans were living with multiple chronic conditions, a figure that is projected to reach 81 million by 2020.⁶⁰ People with chronic conditions need care and treatments that will allow them to live the healthiest, most productive life possible. However, those most in need of health insurance to address their chronic condition are often unable to obtain coverage precisely because of those conditions. Therefore, it is essential for all Americans to be able to obtain and retain affordable coverage regardless of pre-existing conditions.

Employer-sponsored health plans are restricted by federal law from charging an individual higher premiums based on health status or excluding anyone with a pre-existing condition, though they may limit coverage for such a condition under certain circumstances. As more employers stop offering coverage or increase costs that render plans unaffordable to employees, a greater number of people will seek out individual policies. Similarly, those

who lose jobs in difficult economic times will likely be unable to afford to extend their employer-sponsored coverage and will look to individual health insurance plans.

Because individual insurance policies are not subject to the same regulations as group plans, those seeking such policies may find their health precludes them from purchasing coverage or that their insurance does not cover an already-existing health condition. Forty-five states permit insurers to deny coverage based on health history and/or other risk factors. Pre-existing conditions resulting in denial of coverage need not be serious: people have been denied for having hay fever or for taking a common medication to lower cholesterol.⁶¹ In every state, insurers are not required to cover a pre-existing condition during the first six months of coverage while eight states and Washington, DC, allow for exclusion of pre-existing conditions throughout the term of the insurance policy.⁶² In addition, most states have no limitation on a person being charged significantly higher premiums due to their health status.

Those who are unable to purchase an individual policy face the prospect of foregoing medical care or paying for it out of pocket. Although 31 states offer a high-risk pool for people unable to buy insurance, the cost to participate in such programs is too high for the majority of uninsured.⁶³ Seven states do not offer any sort of high risk pool or offer a guarantee that at least one insurer will accept all applicants.⁶⁴ In addition to being costly, these programs often place a cap on benefits, as in the case of California, which limits annual benefits to \$75,000.⁶⁵

Not surprisingly, these barriers prove insurmountable to many seeking individual coverage. A 2005 study found that nearly 90% of those who had sought individual policies in the previous three years did not buy a policy. Cost was a major factor, with 58% having difficulty finding coverage they could afford. Pre-existing conditions resulted in 21% of people being denied coverage, charged higher premiums or having their condition excluded from coverage under their policy.⁶⁶

Another obstacle facing those who have pre-existing conditions—whether or not they are aware of the condition—is the risk of rescission, or having their policy canceled retroactively, when they file a claim. Once a policy has been issued, insurers may continue examining health records and cancel coverage if they discover an applicant has failed to disclose a pre-existing condition or, in cases where they were unaware they had such a condition, if the insurer claims they should have known. One insurer in California canceled nearly 1600 policies over six years in this way.⁶⁷

Providing coverage regardless of pre-existing conditions is essential, but it will not be sufficient unless coverage is equitable for all conditions. Coverage will be incomplete if people find that their condition is subject to restrictions not placed on other illnesses. Therefore, elimination of the restrictions on pre-existing conditions must include a guarantee that the extent of coverage will be the same for all chronic conditions, including mental health and rare disorders. Mental health parity legislation is a milestone in addressing this issue but equity in coverage must be extended to all health conditions.

All Americans require access to affordable care that addresses their medical needs. As long as those with pre-existing conditions face denial of coverage, exclusion for their medical conditions and the threat of having policies canceled retroactively, this need will not be met. Therefore, the restrictions on pre-existing conditions must be eliminated.



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Many insurance policies include limits on annual or lifetime expenses that can prove devastating.



4. Eliminate Lifetime Caps

Health insurance should provide peace of mind to those covered, giving them the security of knowing they will be treated when facing an illness or injury. However, many insurance policies include limits on annual or lifetime expenses that can prove devastating to those requiring costly treatment for catastrophic illness or long-term chronic conditions.

Most people are unaware that insurance policies can include caps on medical expenses. In the course of routine care, such as annual physicals or screenings, there is no need to consider such caps or worry about reaching the set limits. However, that can change in an instant as a result of an accident or an unexpected diagnosis. The consequences can be devastating, as people lose coverage and are forced to pay medical bills incurred in the course of treatment.

The Kaiser Family Foundation's 2007 Annual Survey of Employer Health Benefits found that over half of employer-sponsored plans include lifetime caps, often in the range of \$1–2 million.⁶⁸ In a 2007 survey, 43% of continuously insured (i.e., insured throughout the year) adults whose health coverage “limited the total amount they could spend incurred medical bill problems and unpaid debt compared with 27% of adults who did not have total-dollar limits.”⁶⁹

Although the overall caps sound like unattainable amounts, those with certain conditions can find it easy to reach the limits. The National Hemophilia Foundation notes that patients can spend more than \$200,000 annually just on the medications necessary to prevent bleeding.⁷⁰ Similarly, the president of the Children's Organ Transplant Association states, “it (reaching the cap) does happen pretty regularly in transplant cases.”⁷¹

It's also worth noting that lifetime caps generally do not adjust for inflation. With the rapidly escalating cost of health care, this fact is significant. To keep up with rising health costs, a \$1 million cap in the 1970s would be greater than \$10 million in 2008.⁷²

5. Ensure Access to Long-Term and End-of-Life Care

America's population is aging: the baby boom generation will begin hitting the retirement age of 65 in 2011⁷³ and in 2030, one in five Americans, 71 million people, will be over 65.⁷⁴ These changes will bring unprecedented challenges to the U.S. health care system.

Although Americans are living longer and are generally healthier than previous generations, seniors still have a broad range of health care needs that result from complex conditions. An average 75-year-old has three chronic conditions and uses four or more prescription medications.⁷⁵ Currently, nearly 10 million Americans require long-term care⁷⁶ but this number will certainly rise as the population ages. In 2007, it was estimated that 69% of those who are 65 now will require some long-term care.⁷⁷ The average cost for a private room in a nursing home was \$79,000 in 2006 while the average rate for a home health aide was \$25/hour.⁷⁸

It is imperative that the health care system adapt to meet the needs of this growing segment of the population. It is necessary to ensure that the elderly receive the best,

most appropriate care that is based on respect for the patient's wishes, ensures continuity among providers and avoids placing severe financial strain on either the patient or family caregiver.

The National Academy of Sciences, in its report *Retooling for an Aging America: Building the Health Care Workforce*, found that the health care system is unprepared for these demographic changes. There is a shortage of geriatric specialists and high turnover among other critical health care workers, such as nurses, nurses aides, and home health aides.⁷⁹ In addition, millions provide care for elderly family or friends but have no formal training or needed assistance in the family caregiver role.

In coming years, it will be essential to ensure that more health care workers are trained in the treatment of the elderly, particularly among those who do not specialize in geriatric medicine. It will also be necessary to provide training and support services to family caregivers, who provide the majority of long-term care at a value of more than \$350 billion.⁸⁰ Medical professionals will need to focus on providing high-quality, long-term, individualized care that takes into account the needs and wishes of the patient and his or her family caregivers.

The elderly also face severe financial challenges related to health care. A recent study estimated that a 65-year-old couple retiring in 2008 would need at least \$225,000 in savings to cover medical bills.⁸¹ A follow-up study found that the same couple would need an additional \$85,000 to cover the cost of long-term care insurance.⁸² Many Americans are under the mistaken impression that Medicare, Social Security or private insurance will cover long-term care needs and greatly underestimate the cost of nursing home care.⁸³ While Medicaid does pay for long-term care, many seniors are forced to sell off assets or bankrupt themselves to meet the income qualifications. Long-term care insurance will become increasingly important but cost is currently a barrier to many. Addressing these issues will require policy solutions that ensure health costs do not result in financial ruin and provide a strong safety net for those who do find themselves in dire straits.

Of course, end-of-life care does not just affect the elderly. Respectful care is also essential for those living with terminal illness at any age. As increasing numbers of people make their treatment preferences known through advance directives or conversations with doctors and family, it is critical that the patient's wishes be honored. For many patients facing end-of-life care, quality of life is of paramount importance. Recent research has documented the importance of discussions of end-of-life care between a patient and his or her doctor. One study found that those who have such a conversation often opt for palliative care rather than aggressive treatment. They also do not die sooner than those who do receive more intensive treatment but do die more peacefully.⁸⁴ Equally important as respecting a patient's wishes is the doctor's continued supportive role in the patient's care, even after the patient enters hospice. Patients interviewed in a University of Washington study said they often felt abandoned by their doctor after being admitted into hospice care.⁸⁵

Although a conversation about end-of-life treatment is very difficult, it is necessary, even critical, that doctors and patients engage in this discussion to ensure that the patient's wishes are clear and that doctors can provide exactly the sort of care that honors the patient's choices.



An average 75-year-old has three chronic conditions and uses four or more prescription medications.

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1730 M Street NW
Suite 500
Washington, DC 20036-4561
Phone: 202-785-3910
Fax: 202-785-5923
www.nationalhealthcouncil.org