THE COSTLY CHRONIC DISEASE EPIDEMIC
About the Partnership to Fight Chronic Disease

The Partnership to Fight Chronic Disease (PFCD) is a national coalition of more than 100 patient, provider, and community organizations, business and labor groups, and health policy experts committed to raising awareness of the number one cause of death, disability, and rising health care costs in the U.S.: rising rates of preventable and treatable chronic diseases.

About this Platform

The PFCD believes that the growing prevalence and complexity of chronic health problems are becoming unsustainable challenges for American families, the U.S. health care system and our economy overall. Simply put, we cannot lessen rising health care costs and the economic losses of poor health without addressing chronic disease. Tackling these challenges relies on a willingness to adopt policies that help Americans enjoy better health by preventing and managing chronic illnesses. It is our hope that this platform will help to focus our nation’s leaders — including the 2016 presidential candidates — on the crisis of chronic disease and highlight commonsense reforms that will improve lives across America.

Find out more information at fightchronicdisease.org
The Costly Chronic Disease Epidemic

The increasing burden of chronic disease is the single most important threat to the health of American families and a major drain on the U.S. economy. Today, more than one in two American adults lives with at least one chronic condition—such as diabetes, heart disease, or depression—and nearly one in three lives with two or more chronic conditions.¹

We cannot lower health care costs without addressing the epidemic of chronic disease. The burden of chronic disease is staggering. Eighty-six cents of every dollar spent on health care goes to treating people with a chronic condition. For each additional chronic condition a person has, his or her medical costs increase by more than $2,000 a year on average.² People living with more than one chronic condition spend more out-of-pocket on medical expenses, but medical costs are only part of the burden. Chronic diseases are the number one cause of death and disability in America. Major chronic conditions such as Alzheimer’s can also lead to increased reliance on uncompensated care provided by family members, and lessen overall quality of life.

Health care costs are highly concentrated with 5 percent of the population accounting for more than half of all health care spending.³ Often, these patients have multiple chronic conditions and complex care needs that are not well met by the fragmented way health care is currently structured and delivered. This concentration in costs lends itself to targeted reforms. Compared to a person without any chronic conditions, spending is almost 2.5 times more for those with one chronic condition; 6 times more for people with 3 chronic conditions; and 13.5 times more for people with 5 or more chronic conditions.⁴

Chronic diseases also place a tremendous burden on the U.S. workforce, reducing our competitiveness in the global marketplace. Nearly one in two working age adults (49 percent of those aged 45-64) has more than one chronic condition.⁵ Just two common chronic diseases, diabetes and arthritis, are estimated to cost American families more than $116 billion a year in lost wages and other economic losses in addition to the medical costs of those diseases.⁶ The growing burden of chronic disease is unsustainable. Without change, as the population ages, the number of people living with more than one chronic condition is projected to grow dramatically, driving medical spending, and hindering economic growth.

¹ AHRQ, Multiple Chronic Conditions Chartbook: 2010 MEPS Data.
² Ibid.
⁴ AHRQ, Multiple Chronic Conditions Chartbook: 2010 MEPS Data.
⁵ Ibid.
⁶ CDC, Chronic Disease Overview. Available online at: http://www.cdc.gov/chronicdisease/overview/
There Is Time And Opportunity To Change Course

While not all chronic diseases are preventable, many are, including some of the most common and costly conditions. The World Health Organization estimates that as much as 80 percent of premature heart disease, stroke, and type 2 diabetes and 40 percent of cancers could be avoided entirely if Americans avoided tobacco, developed healthier eating habits, and were more physically active. We could also better manage chronic conditions to prevent costly complications. Chronically ill Americans receive only about half (56 percent) of the recommended preventive care services, such as tests, doctor visits and medicines.

There is also great potential for improved treatments for chronic diseases. For example, a medical breakthrough that delayed the onset of Alzheimer’s disease by just five years would prevent 5.7 million Americans from developing Alzheimer’s and save $367 billion a year within 25 years of its introduction.

To realize the opportunity from improved prevention and management of chronic disease, the Partnership to Fight Chronic Disease believes that America needs health care that

- Prioritizes Prevention and Management of Chronic Conditions.
- Encourages Continued Innovation in Treatment and Delivery of Health Care.
- Improves Access to Recommended Care.
- Promotes Health Across Generations.
- Translates Knowledge into Action.

Based on these guiding principles, we recommend actionable reforms that will improve health for all Americans, whether they have a chronic disease today or are at risk.

1) America Needs A Health Care System That Prioritizes Prevention And Management Of Chronic Conditions.

Our health care system needs to align incentives to encourage payers, providers, employers, and individuals to better prevent, detect, treat, and manage chronic diseases — both physical and mental — before they become acute, costly problems. There is a growing push toward value-based care delivery through which payers pay providers based not only on services provided, but also on health and cost-related outcomes. If new payment models are designed correctly and recognize the importance of personalized care, they have potential to improve the management of chronic diseases, slow their spread, and prevent people from developing multiple chronic conditions.

Linking provider payments to improving quality is an important step forward, but for people with complex health needs, we don’t have the quality measures we need to assure success. For example, people living with multiple chronic conditions are generally excluded from current quality measures, raising serious questions about whether quality will be improved for this population, or if patient health could be compromised in the pursuit of cost control. It will also be critical to ensure that this transformation is done in a way that allows for continued medical progress in the treatment of chronic disease.

Opportunities to Improve Management and Prevention of Chronic Disease:

- **Aligning incentives through carefully designed provider payment reforms.** New payment models must assure access to high-quality care, emphasize improving health outcomes for patients to lower the cost burden of poor health, and allow for continued innovation and support care personalized for patient needs and preferences.
- **Encouraging increased coordination, continuity of care, and care management.** Improvement in these areas is foundational to facilitating the health care system’s transition from an acute care, crisis model to one that is focused on prevention, early detection, and management of disease. Embracing care coordination will improve the delivery of chronic and acute care, reduce errors and wasteful spending, and lessen disparities in care delivery and health outcomes.
- **Empowering and motivating Americans to prevent, detect and manage chronic diseases proactively.** Most of the decisions that affect health take place outside the medical system. Engaging people more directly in their overall health and well-being, and addressing health literacy, socioeconomic issues, and other barriers to better health are critically important.
- **Integrating the primary care provider more completely into the care management process, including behavioral health.** Our nation’s primary health care providers—physicians, physician assistants, nurses, pharmacists, and other clinicians—are instrumental in delivering preventive services and encouraging healthy behaviors. Unfortunately, the health care system is not organized in a way that fully supports them. Behavioral health services are mostly separated from the primary care system, a practice recognized by the Institute of Medicine nearly 20 years ago that leads to inferior care.¹⁰
- **Improving coordination between the traditional medical care system, public health, social services, and community resources.** Poor health often reflects a constellation of issues related to housing, transportation, food insecurity, and other socioeconomic factors. The health care system will be more effective and more efficient if it embraces the resources available outside the medical system that support improved health, including engagement with and referrals to community-based organizations, public health resources, and social services.

¹⁰ Institute of Medicine, Primary Care: America’s Health in a New Era (Washington, D.C.: The National Academies Press, 1996.)
2) America Needs Health Care That Encourages Continued Innovation In Treatment And Delivery Of Health Care.

Our health care system could also become more efficient and effective by adopting and supporting continued development of innovations that enhance quality and outcomes. Continued innovation in use of health IT to support improvements in care delivery and improved management of chronic diseases holds great promise. The value of innovation in medical treatments and technology also cannot be overstated in the fight against chronic disease. Biomedical innovation in America is the envy of the world, fueled by robust investments in research in both the public and private sector. The benefits include longer life with less disability and a strong job growth in health care industries.

Opportunities for Continued Innovation:

- **Giving health care providers accurate, timely information at the point of care to deliver the highest quality, evidence-based medicine using health IT.**
- **Allowing proactive management of patients with chronic illness who may see many providers, take multiple prescription medicines, have more complex medical records, and may require ongoing monitoring by building better systems.**
- **Aiding collaboration among care providers and between the public health and medical care systems by facilitating the interoperability of disease registries and information sharing.**
- **Supporting more effective coordination care and ensuring access to patient and clinical information across a delivery system. To achieve this, health IT must be seamless—interoperable, accessible, usable—wherever the patient obtains services. Efforts should be guided by a better understanding of what patients want from health IT to inform utilization and usefulness.**
- **Facilitating Americans’ ability to track their own health and to obtain information on conditions, treatment options, and quality at the point of decision-making.** Electronic health records (EHRs) can provide patients with valuable information and facilitates collaborative care that includes self-management. The benefits of EHRs, however, depend on their ease of accessibility and use to the patient.
- **Expanding participation in clinical trials by educating health care providers and potential participants about appropriate clinical trial opportunities and by using disease registries and health surveillance systems.**
- **Support policies to incentivize biomedical innovation.** One of the hallmarks of the U.S. health care system is the scope and pace of biomedical innovation and discovery. Continued progress depends upon having an environment that encourages and rewards advances in detection, treatment, and care delivery.

3) America Needs Health Care That Improves Access To Recommended Care.

Americans must have an opportunity to obtain health insurance that supports access to care recommended to prevent and treat chronic diseases. Having health care coverage is important, but does not necessarily mean care is affordable and accessible to the people who need it. Chronically ill Americans receive only about half (56 percent) of the recommended...
Opportunities to Improve Access

• Removing barriers to comprehensive prevention, early detection, and intervention, and disease management resources. Better understanding and removing barriers to care seeking and adherence to treatment for chronic conditions, including high cost-sharing, should inform benefit design and health care financing models.

• Ensuring that consumers have easy access to consumer-friendly information when shopping for health insurance. For all consumers, but particularly those with chronic conditions, knowing what providers, medicines, and medical equipment are covered preventive care services.

Skipping appointments, not filling prescriptions, and testing less often than recommended represent missed opportunities to improve health that drive costs higher. For example, the IMS Institute has estimated that improving medication adherence alone could save the U.S. $105 billion a year.

A recent poll of emergency department physicians found that 7 out of 10 doctors had insured patients who had delayed care because of out-of-pocket expenses. Accordingly, programs aimed at reducing preventable hospitalizations, readmissions, and other intensive care services by providing better access to chronic care management not only save money, but also reduce out-of-pocket spending for people with complex health care needs.

There are also rising concerns about shortages among primary care providers. Many underserved areas in the country already have provider shortages, impacting health status in those communities. As of June 2014, there are approximately 6,100 geographic areas with primary care shortages with less than one physician for every 3,500 people, and projected primary care shortfalls range from 12,500 to 31,000 physicians by 2025. Fully integrating physician assistants and primary care nurse practitioners into the health care delivery system could assist with primary care shortages, though several states are projected to experience nursing shortfalls.

Opportunities to Improve Access

• Removing barriers to comprehensive prevention, early detection, and intervention, and disease management resources. Better understanding and removing barriers to care seeking and adherence to treatment for chronic conditions, including high cost-sharing, should inform benefit design and health care financing models.

• Ensuring that consumers have easy access to consumer-friendly information when shopping for health insurance. For all consumers, but particularly those with chronic conditions, knowing what providers, medicines, and medical equipment are covered preventive care services.

is critically important when choosing a health plan. To make informed decisions, consumers need ready access to understandable information about what’s covered, what’s not covered, and true out-of-pocket costs in addition to premiums.

- **Building the workforce of primary care providers in underserved areas and leveraging the full spectrum of health care workers.** Health care workforce shortages are well-documented and compromise access to care particularly in underserved areas. Many in the health care workforce — such as pharmacists, patient navigators and community health workers - are underutilized and could help to fill these gaps, making care more accessible and affordable.

- **Facilitating access to community-based services.** Community-based programs provide aging in place services, disease management coaching, and preventive care services in lower cost settings with proven results. Integrating these services more closely with the healthcare system can increase support for patients and families while reducing health care costs.

**4) America Needs Health Care That Promotes Health Across Generations.**

Good health habits established in childhood carry the promise of better health throughout life. However, when it comes to health improvement, we are failing our children. The prevalence of chronic health conditions among children in America has risen dramatically in a generation. For example, childhood obesity rates alone have more than tripled just since the 1970’s.\(^\text{18}\)

Poor health status headed into adulthood presents challenges for employees and employers and hinders economic growth overall. For example, the U.S. Army estimates that 28 percent of applicants are rejected for medical reasons, including weight.\(^\text{19}\) Preventable and poorly managed chronic diseases also drive workplace health care costs, including productivity losses.\(^\text{20}\) Better management of chronic diseases like depression\(^\text{21}\) and addressing risk factors such as obesity\(^\text{22}\) and smoking\(^\text{23}\) could help qualified workers stay on the job, improving competitiveness of the American workforce.


\(^{20}\) CDC, Workplace Health Promotion: Worker Productivity. Available online at http://www.cdc.gov/workplacehealthpromotion/businesscase/reasons/productivity.html


Opportunities to Improve Health Across Generations

- Promoting wellness in the workplace. Recognizing the positive bottom line impact of having a healthier workforce, large and small employers are investing in workplace wellness. Estimated savings from well-designed programs show that each dollar invested saves more than three dollars in medical costs and more than two and a half dollars in losses from missed work days. To facilitate workplace wellness promotion, clear legislative and regulatory guidance is needed to assure compliance with privacy and anti-discriminatory legal protections.

- Incorporating health promotion and disease prevention and management into the everyday routines of American children and families. Policies that improve access to safe places to be active, to encourage healthy food consumption, to avoid and cease tobacco use, to reduce exposure to harmful chemicals, and to empower healthy decisions through education and awareness can make a significant difference today and for future generations.

- Improving support for those with family caregiving responsibilities. At some point in their lives, most Americans will be called upon to provide uncompensated care for a loved one. About 80 percent of care at home is provided by unpaid family caregivers—many at the sacrifice of their own health. As part of an integrated and holistic approach to caring for the chronically ill, these families need opportunities for respite care and social support networks, which can make caregiving more manageable.


In communities across the nation, people have developed innovative programs that promote wellness and prevent and manage disease. We aren't doing enough to tap into that knowledge and to replicate nationwide those programs that work. The need to replicate successful programs is particularly acute in underserved areas and with populations in which health disparities persist, lowering health status and leading to lost economic opportunities.

In the appendix we suggest best practices that could be spread more broadly to improve management of chronic disease, reduce health care costs, and lead to a more productive workforce and stronger U.S. economy.

---

Appendix: Case Studies

Managing Chronic Disease: Better Choices, Better Health®
Stanford Chronic Disease Self-Management Program

This well-tested model relies on community-based or online workshops for people with chronic diseases led by peer coaches with health problems of their own. Workshops focus on building self-management skills, sharing experiences, and offering support. Consistent participant results include greater energy/reduced fatigue, more exercise, fewer social limitations, better well-being, enhanced partnerships with physicians, improved health status, and greater self-management skills. Participants also demonstrated more appropriate utilization of healthcare services that maintain even with declines in health, and cost-savings in reduced utilization of emergency care, hospitalizations, and other intensive services.


Comprehensive Coordinated Care: CareMore

CareMore, identified in Health Affairs as a “medical home run,” is a high-touch, coordinated care delivery model for Medicare beneficiaries and other populations. The model focuses on prevention and team-based care that generates clinical outcomes above the national average while keeping costs an estimated 15 percent below average. Pivotal features include exceptional individualized caring for chronic illness to prevent ER visits and unplanned hospitalizations, efficient service provision through a focus on chronic conditions and utilization of a full range of care providers, and careful selection of and coordination with medical specialists.


Behavioral Health Integration: COMPASS

The COMPASS care model (Care of Mental, Physical, and Substance-Use Syndromes) integrates behavioral health into primary care. A primary care practice-based care manager meets weekly with a consulting psychiatrist and consulting primary care physician to review the care of patients with depression and at least one other chronic disease. Together, the team evaluates progress on medical and patient-identified health goals. The care managers, typically nurses, social workers, psychologists, or specially trained medical assistants, also address individual patient barriers to health improvement. Program evaluation under a CMS grant continues, but preliminary results show positive outcomes on diabetes blood sugar control, remission of depression, and blood pressure management.

Preventing Chronic Disease Development in At-Risk Populations: Diabetes Prevention Program

By 2020, nearly half of American adults will have diabetes or prediabetes, which will cost the U.S. $3.35 trillion over this decade. The well-tested Diabetes Prevention Program continues to generate significant results in preventing the onset of diabetes in people with pre-diabetes. Adapting the program to a lower-cost community setting has broadened the reach of the program and increased accessibility. Many private insurers and employers provide access to the program, but traditional Medicare currently does not. Offering the program to adults ages 60-64 at risk is estimated to save Medicare $7 billion or more over the lifetime of those participants. The program is now being tested as part of a Centers for Medicare and Medicaid Innovation grant in Y’s across the U.S. and is offered as a part of community-based programs at Y’s and other community venues across the nation. For people diagnosed with diabetes, Diabetes Self Management Training/Education (DSMT) taught by credentialed diabetes educators has proven to improve outcomes and lower costs.


Improving Health for School Children: Asthma-Friendly School Initiative

The Centers for Disease Control and Prevention, the American Lung Association, and the National Association of School Nurses partnered to develop and implement the Asthma-Friendly School Initiative. The program includes evidence-based tools and resources for schools and communities to create sustainable asthma management plans within existing school health structures. The tools highlight how small changes can make a significant difference. For example, New Hampshire schools developed guidelines on school bus idling to reduce diesel exhaust from school buses, protecting the health of drivers, children riding the bus, and children and staff exposed at school.

Promoting Workplace Wellness: Douglas County School District (CO)

The Douglas County School District has set its sights on being the healthiest school district in the United States, and receiving a Silver Welcoa Workplace-Wellness award in 2015 shows the district is on its way. The District's strategy included an employee-approved comprehensive wellness plan and a new health benefits plan. Fun programs, including weight loss challenges and staff sports, are motivating to employees as well as students and their families broadening the focus on health to the community at large.

Team-Based Care for Vulnerable Populations: Iora Health

The Culinary Extra Clinic, an Iora Health clinic in Las Vegas, serves low-wage hotel and casino workers with multiple chronic conditions. Physicians, health coaches, social workers, and other care providers work collaboratively to help patients better manage their health and address barriers to better health that extend beyond a traditional office visit. Services are made available to patients in person, by phone, or by email and include linking patients to community resources and providing education to support healthy behaviors like healthy cooking, exercise, and tobacco cessation. A study of the Iora Health model found that it reduced ER visits by 48 percent, hospitalizations by 41 percent, and health care costs by 15 percent.


Addressing Childhood Obesity within Families: MEND Program

The YMCA of the USA (Y-USA) and Healthy Weight Partnership, Inc. have entered a long-term partnership that allows Y’s across the U.S. to offer the Mind, Exercise, Nutrition...Do it! (MEND) program. MEND is one of the world’s largest evidence-based childhood obesity program that works both with youth affected and their families to attain a healthy weight.


Supporting Caregivers: Help for Cancer Caregivers

Help for Cancer Caregivers is a free, internet-based resource for caregivers of people living with cancer. The resource provides information, education, and support that helps caregivers care for themselves as well as their family members battling cancer. Born from the realization that chronic conditions, including cancer, not only affect the individual but his or her family and support network, the Caregiver Action Network, CancerCare, Indiana University, Michigan State University, Takeda Oncology, and Anthem, Inc. collaborated to develop the resources to support caregivers.
