When it comes to health care, the United States is witnessing two fundamentally incompatible trendlines. High-deductible health plans (HDHPs) represent an increasing share of the health insurance Marketplace. Nearly 70 percent of mid to large employers offer HDHPs to employees and for 13 percent, an HDHP is the only option offered. In
2011, roughly a quarter of Americans between the ages of 18 and 64 had HDHPs as their primary insurance either through an employer or individually purchased. In 2016, that share had grown to 39.3 percent. One in four covered employees now have single-person deductibles of at least $2,000 a year.

At the same time, there is a significant number of Americans who cannot simply elect to limit their use of health services or can do so only by risking severe consequences. For the 60 percent of Americans living with at least one chronic condition, high deductibles present precarious financial conditions that recur every January 1. As the National Center for Health Statistics has reported, people with HDHPs are far more likely than those with traditional health plans to forgo or delay medical care or to be in a household that is having difficulty paying medical bills. Relatedly, as Suzanne F. Delbanco and Roslyn Murray noted in a prior Health Affairs Blog post, consumers insured through HDHPs tend to use less care overall, including high-value care needed to preserve and improve health.

To address this crisis, we propose a national dialog that starts by acknowledging that:

- Shifting costs onto people living with chronic conditions is not a solution to lowering health care costs;
- HDHPs mean people with serious chronic illnesses must pay their entire deductible early each year or forgo the care they need;
- Health Savings Accounts (HSA) are not sufficient to resolve the problem alone; Holistic solutions require involvement of health plans, employers, providers, patients, and caregivers; and
- Solutions must enable people to have affordable access to the care they need to maintain their health throughout the year.

As illustrated below, serious and life-threatening diseases do not wait for financial concerns. Not dealing with this cyclical issue will continue forcing people with chronic disease to make choices with potentially serious unintended consequences. And unfortunately, as we explain, there are serious flaws in many of the approaches commonly suggested to lessen the burden of HDHPs for those with chronic diseases.

**The High, Up-Front Expense Of Cancer Care**

For the 1.7 million Americans diagnosed with cancer each year, medical care becomes very expensive quickly. As described in a groundbreaking report by the American Cancer Society, a person diagnosed with cancer in January will have to pay his or her entire deductible in the first quarter of the year to have necessary diagnostic testing as well as
possible surgery, radiation, and chemotherapy. Because cancer is a disease that must be treated with a degree of urgency to halt its progression, costs are front-loaded in the form of immediate scans and subsequent surgeries or therapies, and delays can have consequences.

A more recent study found that women with breast cancer who had switched to HDHPs before being diagnosed experienced delays in every aspect of the care process: diagnostic imaging, biopsies, early-stage diagnoses, and chemotherapy treatments. Related research noted that delays occurred regardless of income status, although delays were longer for women with lower income levels.

Living A Quality Life With Epilepsy

According to the Centers for Disease Control and Prevention (CDC), a little more than 1 percent of the US population has active epilepsy—approximately three million adults and almost half a million children. For this population, quality of life—including maintaining a job (as a patient or caregiver), having driving privileges, and avoiding mental health challenges that can accompany epilepsy—and often life itself hinge on the ability to control seizures.

Regular adherence to medication protocols is critical. As the Epilepsy Foundation points out, “Missing doses of seizure medicine is the most common cause of breakthrough seizures. Missed medicines can trigger seizures in people with both well-controlled and poorly controlled epilepsy. Seizures can happen more often than normal, be more intense, or develop into long seizures called status epilepticus,” medical emergencies that can lead to death if not stopped. Missing doses can also lead to falls, injuries, and other problems from seizures and changes in medicine levels in the body. A review of studies has shown that direct, epilepsy-related medical costs associated with uncontrolled epilepsy are 2 to 10 times higher than costs associated with controlled epilepsy.

Yet, research has also demonstrated that increases in out-of-pocket spending for antiepilepsy medications—such as one would experience in an HDHP—have had negative effects on the consistent usage of antiepileptic medications and, consequently, have increased in epilepsy-related and overall health care spending. The Epilepsy Foundation reports receiving a surge in requests for financial and coverage assistance in January, revealing the struggle that many face obtaining needed health care services and medication due to the structure of these HDHPs.
High Health Care Needs For People With Autoimmune Diseases

More than 23.5 million people in the United States have some form of autoimmune-related disease(s) such as multiple sclerosis (MS) or rheumatoid arthritis. And, according to the CDC, 54 million adults have at least one of 100 types of joint disease. For these individuals, medication is just one of the health care expenses they face. They also frequently require physical therapy as well as various types of durable medical equipment.

For many, HDHPs present a challenge in accessing the services needed to treat their condition and to enable mobility and socialization. Rheumatologists report that people with arthritis skip physical therapy treatments that could enhance their well-being due to high out-of-pocket costs. A rheumatologist at the University of Kentucky observed, “We see decreased utilization at the beginning of the year when deductibles have not been met, and an increase at the end of the year, trying to get in treatments before the year ends. I see delays in necessary procedures due to costs and patients unable to afford medications due to increased cost.”

Nearly one million Americans, more than twice the number previously believed, have MS. Life with MS can mean dealing with a wide range of difficult symptoms, including fatigue, cognitive changes, blurred vision, numbness, chronic pain, depression, and bladder and bowel dysfunction. Disease-modifying therapies (DMTs) for MS slow natural disease progression, help reduce the frequency and severity of MS attacks, and may slow the progression of disability. The National Multiple Sclerosis Society recommends that a person consider treatment as soon as possible following a diagnosis of MS. Evidence suggests that treatment needs to be ongoing for benefits to persist, and gaps can have deleterious results.

A study examining pharmacy and medical claims data over an eight-year period found that higher out-of-pocket costs significantly lowered the likelihood of someone with MS receiving disease-modifying therapies. Moreover, “Previous research indicates that poor DMT adherence is associated with a higher risk of MS-related hospitalization, emergency department visits, relapse, and MS-related medical costs.”

Often-Discussed Solutions Do Not Address The Problem

There is a growing awareness of the financial dilemmas facing individuals in HDHPs who have serious chronic illnesses. However, that awareness has not yet generated
widespread workable solutions to the problem.

Recognizing the challenges of HDHPs and deferred medical care, a few large employers have announced reduced deductibles or other assistance for employees at certain income levels. According to a 2016 survey, however, only 4 percent of employers had instituted some form of health coverage assistance for low-wage employees. Also, targeting assistance based upon income does not address the core challenge involved here. The high cost of serious chronic illness can devastate the finances of a middle-class family just as it can a low-income one.

Similarly, suggestions that working Americans can cushion themselves with HSAs do not reflect objective realities. For someone who is struggling with a condition such as cancer or heart disease, it is unrealistic to cover the costs associated with high deductibles and copayments and, at the same time, contribute funds to an HSA even when the option is available. A recent Willis Towers Watson survey revealed that one in four people who do not enroll in an HSA do not have enough money to contribute. Meanwhile, 63 percent of those who do enroll say they put aside as much as they can afford, but fewer than half have more than $5,000 saved. Even when people are able to put money into an HSA, those with high health care costs are rarely able to accumulate HSA savings. That means starting over each year with a high-deductible phase with little to no HSA savings to help defer costs.

Other avenues of support are episodic and sporadic instead of systemic and holistic. For example, a growing number of hospitals and medical group practices are offering low-interest or no-interest payment plans for people who cannot pay for care upfront, even though insured. Some employers are offering lower deductibles for low-wage employees. There are patient assistance programs that help reduce out-of-pocket costs for prescription drugs for those who qualify, although payers and others argue such programs contribute to the escalation of prescription drug prices and are impeding access to them.

Potential Paths Forward

We need solutions that are targeted toward disease status and designed to meet the needs of those who face the kind of gap between expenses and what their health insurance will cover that leads to financial crisis. Essentially, the difference between conventional health plans and HDHPs is creating a tiered health system separating those with broad access to care from those without, particularly for those facing the often high expense of chronic disease. According to one study, 48 percent of families with chronic conditions in HDHPs were dealing with financial stress connected to health care costs,
compared to just 21 percent in conventional health plans who reported the same financial burdens. The increasing availability of low-premium, limited-benefit health plans—sometimes known as “skinny” plans—could exacerbate the financial challenge facing households dealing with chronic illness.

Both public and private payers increasingly seek mechanisms that will help reduce their health care costs by shifting more responsibility to the consumer, But, we need broader solutions than simply curbing short-term costs for payers by causing people living with chronic diseases to defer needed care, leading to poorer health and greater health care use in years to come.

Ideas to seed the national dialog we call for are out there—for instance, Delbanco and Murray note the possibility of exempting certain services from the deductible for all enrollees in HDHPs, or more radically, Altarum’s Medical Episode Spending Account would provide a budget for major medical needs outside the deductible. These and other ideas need to be evaluated and discussed.

Although HDHPs have a place as health care coverage options, people living with chronic conditions need different choices. Approaches that fail to acknowledge the crippling financial burdens associated with serious, chronic illnesses are destined to leave millions of Americans facing deepening economic distress.