

REDUCING THE BURDEN OF CHRONIC DISEASE

A Report of the Aspen Health Strategy Group



Foreword by Kathleen Sebelius and Tommy G. Thompson

Edited by Alan R. Weil and Rachel Dolan



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The mission of the **Aspen Health Strategy Group** is to promote improvements in policy and practice by providing leadership on important and complex health issues. The group is comprised of 24 senior leaders across influential sectors including health, business, media, and technology, and is part of the Health, Medicine and Society Program at the Aspen Institute. Co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former governors and former US Secretaries of Health and Human Services, the Aspen Health Strategy Group tackles one health issue annually through a year-long, in-depth study. This book is a collection of papers on the group's third subject: prevention of chronic disease. The papers address topics related to the financing, services and ethical issues related to chronic disease, and includes a final consensus report based on the group's work.

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January 2019

I am delighted to introduce the third annual report of the Aspen Health Strategy Group (AHSG), which explores the challenges associated with chronic disease, and offers a package of “Big Ideas” to address them. The product of rich research and thoughtful discussion, this volume continues the AHSG tradition of diving deep into a single health policy and practice issue every year. Past reports have tackled end-of-life care and the opioid epidemic.

The AHSG, a project of the Aspen Institute’s Health, Medicine and Society Program, is co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former US Secretaries of Health and Human Services (HHS) and former governors. The 24 members include CEOs and other high-level executives at major corporations, health systems, professional associations, and foundations, as well as innovative thinkers in academic settings. They are joined, as well, by five former HHS secretaries who serve in an ex officio capacity.

Together, these thought leaders steep themselves in the controversies and opportunities surrounding their chosen topic and engage in intensive learning and discussion sessions designed to drive consensus. In confronting chronic disease, the AHSG has taken on an issue responsible for seven of the top ten causes of death, and one that accounts for more than 86% of the nation’s health care spending.

The work of the Aspen Health Strategy Group honors the Aspen Institute’s core principles of rigorous non-partisanship and respect for evidence, and its reputation for putting together forward-focused thinkers and doers. The influence, prestige, and commitment of AHSG members, and their determination to help solve some of the nation’s most vexing health problems, place them at the center of current conversations on human wellbeing. We are deeply grateful for their efforts.

All the best,

A handwritten signature in black ink that reads "Dan Porterfield". The signature is written in a cursive style and is positioned above the printed name.

Dan Porterfield
President and CEO
The Aspen Institute



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Foreword

Kathleen Sebelius
AHSG Co-Chair

Tommy G. Thompson
AHSG Co-Chair

This is our third year as co-chairs of the Aspen Health Strategy Group, and we are proud of the group's success in promoting improvements in policy and practice by providing leadership on important and complex health issues.

This year we selected chronic disease as our topic. Chronic diseases are the leading cause of death and disability in the United States. More than half of adults over age 18 have at least one chronic condition. One quarter have at least two. The health care costs associated with these diseases are astronomical, accounting for 86% of the nation's \$2.7 trillion annual health care expenditures in 2014. In June 2018, the Aspen Health Strategy Group met for three days and took on hard questions related to this complex issue.

We are pleased to present the final report from our work, based upon our group's rich discussion. In the tradition of the thought-provoking conversations and dialogue on how to address critical societal issues -- the hallmark of the Aspen Institute -- the report includes five big ideas to prevent chronic disease. In our



discussions, we relied heavily upon four background papers, prepared by subject matter experts. Those papers are included in this compendium as well.

Each background paper was written by a subject matter expert. Ken Thorpe provided the background on chronic conditions in the US. Dana Goldman and coauthors summarized our fragmented way of paying for treatment of chronic conditions and how our financing system is at odds with our prevention goals.



In the tradition of thought-provoking conversations and innovative ideas on solving critical societal issues -- the hallmark of the Aspen Institute -- we are looking for big, bold and "out-of-the-box" proposals to help our nation prevent chronic disease.

Each year, the AHSG tackles one issue for a year-long, in-depth study. The first subject was how to improve end-of-life care. Last year's topic was confronting the nation's opioid crisis. This year we are tackling prevention of chronic disease. As a country, we need new ideas -- changing dietary guidelines and encouraging physical activity clearly aren't moving the needle enough -- to address this complicated health challenge.

AHSG members know that good ideas can come from anyone. If you have a big idea for preventing chronic disease, we hope you will share it with us by filling out a short form. Our broad, public call for ideas will last until June 8th.

For complete information about our guidelines, and to submit your big idea, go to <http://aspeninstitute.org/AHSGBigIdeas>.

Vincent Lafronza and Lisa Tobe described community models to prevent chronic disease and the importance of addressing upstream factors. Barbara Redman reviewed the ethical issues related to the lack of successful treatment of and the need for research on chronic disease. We were fortunate to have five of the authors present for the discussion in Aspen, in addition to Mollyann Brodie from the Henry J. Kaiser Family Foundation, who provided again this year, valuable data regarding public opinion on chronic disease.

Before our meeting we issued a broad call to the public for their ideas for how to address chronic disease. We benefited from all of the ideas, but we particularly want to acknowledge the following individuals and organizations for submitting ideas that made their way, often with modification, into the final big ideas adopted by the group: Rebecca Battista, Appalachian State University; Marc Boutin, National Health Council; Teresa Bubbers, Viterbo University; Amy Buch, Orange County Health Care Agency; Dave Chokshi, NYC Health + Hospitals; Alexandra Larcom, International Health, Racquet, and Sportsclub Association (IHRSA) and American Council on Exercise (ACE); Steven Manson, Gundersen Health System; Sal Migliaccio, AmeriCare; Nick Nichols, La Crosse County; Jean O'Connor, Task Force for Global Health; Caroline Poplin, Arlington Free Clinic; Stefanie Rinehart, Academy of Nutrition and Dietetics; John Rother, National Coalition on Health Care; and Peter Verdin, Athlos Academies.

We are also grateful to the two organizations that provided funding to make this work possible. We received generous financial

support from the Robert Wood Johnson Foundation and the Laurie M. Tisch Illumination Fund. The perspectives expressed in this report are those of the authors and do not necessarily reflect the views of either of the organizations. On behalf of the Aspen Health Strategy Group and all those associated with its activities in 2018, we thank them for their support and continued commitment to this effort.

Dedication

This report is dedicated to the members of “The Bigger Picture,” a program designed to change the national conversation about Type 2 diabetes.

We are particularly grateful to Ivori, Edgar, Ciera and Ryane, whose participation in the opening session of our meeting helped guide and ground our discussion.



Members of The Bigger Picture
(learn more about The Bigger Picture at thebiggerpictureproject.org)

ASPEN HEALTH STRATEGY GROUP REPORT

**Five Big Ideas to Reduce the
Burden of Chronic Disease**

Part 1



“Based on the evidence presented to us, we conclude that the single most consequential step the nation could take to reduce the burden of chronic diseases is to reduce the incidence of obesity.”

– THE ASPEN HEALTH STRATEGY GROUP

Five Big Ideas to Reduce the Burden of Chronic Disease

Introduction

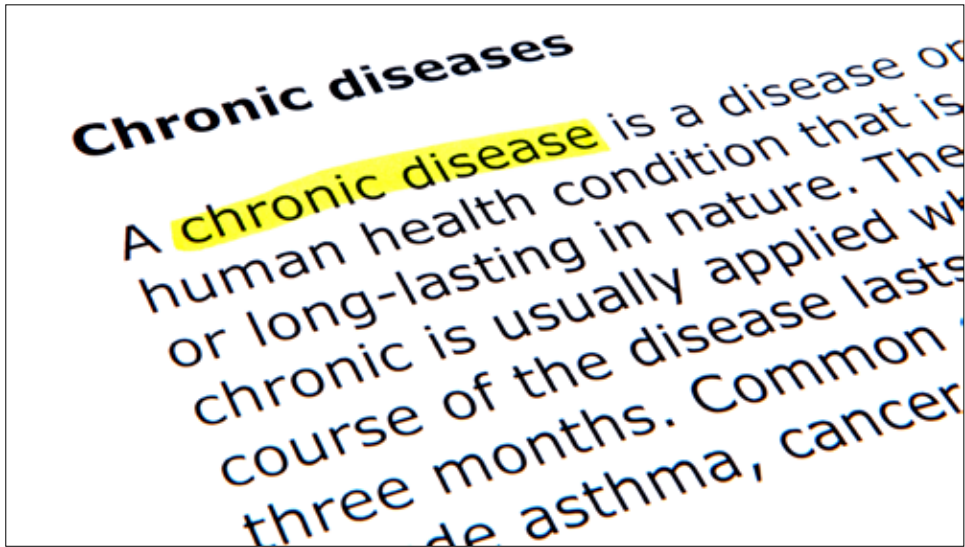
Chronic diseases, generally defined as conditions that last one year or more and require ongoing medical attention or limit daily activities, are the leading causes of death and disability in the United States. Common chronic diseases include hypertension, heart disease, and diabetes. Most chronic diseases cannot be cured, but most can be managed in ways that reduce the daily burden of the disease and/or the likelihood it will progress to more serious symptoms.

More than half of adults ages 18 and older have at least one chronic condition; more than one-quarter have at least two. Eighty-six

percent of the nation's \$2.7 trillion annual health care expenditures in 2014 were on behalf of people with chronic diseases and mental health conditions. Seven of the top ten causes of death are associated with chronic diseases including heart disease, cancer, chronic respiratory disease, stroke, Alzheimer's, diabetes and chronic liver disease.

The Aspen Health Strategy Group selected prevention of chronic disease as its topic for discussion in 2018, its third year. This group of leaders in and outside health care spent three days considering the topic with the assistance of subject matter experts who prepared four background papers to frame the conversation. In our discussions the group quickly came to the conclusion that addressing chronic diseases means taking on obesity – because so many diseases are directly associated with that condition. The group emerged with five big ideas to tackle obesity in order to reduce the burden of chronic disease.





The Aspen Health Strategy Group’s goal is to promote improvements in policy and practice by providing leadership on important and complex health issues. Co-chaired by Kathleen Sebelius and Tommy Thompson, both former governors and former US Secretaries of Health and Human Services, the group is composed of 24 senior leaders across sectors including health, business, media, and technology. (More information about the Aspen Health Strategy Group can be found at www.aspeninstitute.org/health.) This report captures the deliberations of the group, but no specific proposal or statement in the report should be considered to represent the opinion of any individual member of the group.

Background

“Several factors, most of which are outside the traditional health care system, affect chronic disease prevalence, morbidity and mortality rates. These determinants of health include environmental factors, socio-economic status, transportation, genetics, lifestyle and behavioral factors, social services and education,” says Kenneth Thorpe in “Understanding and Preventing Chronic Disease.”

The prevalence of chronic disease and the number of patients with multiple chronic conditions have increased markedly over the past two decades. Compared to 8% in 1995, 18% of adults were treated for five or more chronic diseases in 2015. The costs of treating chronic diseases are also high: As of 2016, chronic diseases accounted for more than \$2 trillion in health care spending per year and about six out of every seven dollars spent on health care.

Obesity underlies most chronic diseases. Obesity is a risk factor for type 2 diabetes, hypertension and hyperlipidemia. Nearly 40% of the adult population is now considered obese, a tremendous increase from 15% 30 years ago. The rise in obesity rates, along with increasing intensity of how we treat chronic diseases, accounts for 20% to 30% of the growth in health care spending since 1987.

Chronic disease prevalence varies by race and ethnicity. According to Thorpe: "Non-Hispanic blacks are 55% more likely to be diabetic, 60% more likely to have high blood pressure and 56% more likely to have cerebrovascular disease than non-Hispanic whites." Some of this difference is associated with different rates of obesity across these population groups. Compared to an obesity rate of 34.5% among non-Hispanic whites in 2014, 48% of non-Hispanic blacks were obese and 43% of Hispanics of any race were obese.

Thorpe calls for preventive approaches to mitigate the growth in behavioral risk factors associated with chronic diseases. In particular, "population-based health programs that integrate social, health care, and other determinants of health could represent the next generation of approaches to reducing the burden of chronic disease." As an example, he cites positive results from the YMCA's diabetes prevention program.

In "Investing in Prevention to Address the Burden of Chronic Disease and Mental Health," Dana Goldman, Seth Seabury, and Sarah Brandon tell us "The United States is becoming a victim of its demographic success. While Americans are living longer, they are not necessarily living healthier. Disability rates have been rising, due in large part to the prevalence of major chronic diseases such as high blood pressure, heart disease, diabetes, cancer, and stroke among our elderly."

According to Goldman and colleagues, the short-term orientation of the US health care system impedes long-term investment in prevention. Insurance policies last one year and health plans reimburse for a patient in the hospital but don't pay appropriately to keep them out of one.

The fragmented nature of the US health care system also contributes to increased treatment costs associated with chronic diseases. Poor coordination in diagnosis and care delivery particularly affects those with chronic conditions, who often have multiple care providers and need treatment for multiple comorbidities. Lack of effective communication between primary care providers and specialists contributes to underutilization of effective prevention and makes it harder for patients to manage their chronic conditions. These inefficiencies increase costs and place a burden on patients.

Goldman and colleagues report simulation results of the economic and health effects of increasing the use of aspirin¹, preventing heart disease, and delaying the effects of aging. They show significant positive returns to investing in prevention. However, they point out, current payment models discourage innovation in prevention technology and early interventions. This must change in order to realize the benefits of prevention investments: “The key to reaping the fruits of that labor will be our ability as a system to move to a model that rewards positive health outcomes, not health care resource use.”



“Focusing on downstream solutions, such as raising awareness about risk factors, providing access to health care or telling people to change their behavior does little to address the root causes of health inequities,” write Vincent Lafronza and Lisa Tobe in “Models to Prevent Chronic Disease and Create Health in Communities.” Clinical health care accounts for only 20% of modifiable determinants of health; social and economic

factors, health behaviors and physical/environmental factors make up the vast majority. Racism, violence, food insecurity and the built environment all have a quantifiable effect on health. Differences in chronic disease incidence account for a large portion of the life expectancy gap between blacks and whites. These disparities are attributable to a number of factors such as socioeconomic status, smoking, diet, and access to care, although even after accounting for these factors unexplained racial differences remain.

Government programs and policies of regulation and taxation designed to promote prevention, healthy eating, active living, and tobacco control could decrease chronic diseases. These policy levers can reach a large share of the population. According to various studies the authors cite, in the first year of implementation, a national sugar sweetened beverage tax would reduce consumption of sweetened beverages by 20%, reduce mean body mass index (BMI) by 0.16, and prevent the loss of more than 100,000 disability-adjusted life years. A 2009 change in the federal Women, Infants and Children (WIC) program encouraged purchases of

¹ The simulation was conducted prior to recent evidence that brings into question the value of daily aspirin use.

healthier foods and led to decreased juice purchases and increased fresh fruit and vegetable purchases. Further cigarette tax increases would reduce cigarette consumption. The authors provide eight examples of multisector initiatives underway throughout the United States that address social determinants, reduce disparities, and have multiple partners and funding sources.

Interventions at the community level are also critical to prevent chronic disease. Structural barriers to racial equity must be removed. “Creative placemaking” initiatives allow a community to invest in the design and reinvention of its public space and promote wellbeing for its residents. Community-based efforts can consider the totality of resources and make efforts to allocate them in ways that support residents’ health.

In “Ethical Issues in Responding to Chronic Diseases,” Barbara Redman writes “The health care system’s response to the growing prevalence of chronic disease ... has been inadequate, with excessive reliance upon patient self-management and too little introspection by those in the health care sector regarding the systemic changes needed to orient care to meet these growing needs.” A societal attitude that emphasizes “personal responsibility” places the onus for adopting healthy behaviors on individuals. Recent trends toward “patient activation” continue this push of responsibility to individuals and patients with little regard for their knowledge and ability to effectively monitor and manage their conditions. Despite growing understanding of the importance of social determinants of health, doctors are increasingly held responsible for patient behavior that reflects policies and factors outside their control.



“What we choose to treat or leave untreated, where research dollars are invested and how research subjects are approached, are normative (ethical) decisions,” writes Redman. To address these shortcomings, the health sector must address chronic disease as a health disparity and must redesign care management around a “capability approach” by focusing on what individuals are able to do.

Framing the Issue

Four themes emerged in the group's discussions that helped guide the development of this year's big ideas. The themes are:

- **The rapid growth in chronic disease is a national crisis.**

The dominant role chronic conditions play in our health care system is now well established. In 2015, 65% of adults had at least one chronic condition and 86% of health care spending was associated with people with chronic conditions.

It would be gratifying if the growth in chronic conditions were a success story related to growing life expectancy. After all, longer life spans provide more opportunity for chronic conditions to develop. Improved heart attack and stroke care keep people living, often with chronic conditions. A cancer diagnosis, once a death sentence, is now, for many, a manageable life-long condition.

We could tell ourselves a similar success story about the rising prevalence of multiple chronic conditions. Instead of killing us, a single condition such as diabetes can be managed, giving the body time to develop another chronic condition, such as heart disease. Advances in acute care mean if a single chronic disease leads to an acute episode, such as a heart attack, the person is more likely to survive another day, and live long enough to develop multiple chronic diseases.

But it turns out this positive story is wrong. While chronic diseases are more prevalent as people age, as the data presented above show, we are now diagnosed with those diseases at earlier and earlier ages. The same is true for multiple chronic conditions.

Put simply and starkly, people are becoming sick, and becoming increasingly sicker, earlier in life than occurred in the past. And our children are bearing a particularly heavy burden. Life expectancy at birth is falling. Declining life expectancy among those of middle age are thought by some to be "deaths of despair" arising from substance use and depression. But declining life expectancy at birth is primarily associated with the dramatic rise in the early onset of chronic conditions.

Disparities in the prevalence of chronic conditions are a central element of the racial and ethnic disparities that exist with respect to life expectancy and health status. Responding to the chronic disease crisis is an essential step toward health equity.

As Barbara Redman explains in her paper, much of the health care system has adopted an approach of patient self-management when it comes to chronic conditions. Patients are expected to learn for themselves how to modify their behaviors in response to the onset of a chronic condition. Those that fail to do so are labeled “non-adherent” and may be treated poorly by the health care system. Unlike with acute conditions, worsening of the patient’s condition is often treated as a personal failure, rather than a system failure. This stands in contrast to a shared responsibility approach, in which the health care system engages patients and supports patient capabilities in a non-judgmental manner.

Many chronic diseases bring with them an increase in patient social needs. While parts of the health care system are reorienting toward these needs, the clinical focus of most care leaves those needs largely unmet.

This health crisis brings with it a cost crisis – a crisis that burdens all who pay for health care with a particularly heavy burden on those with chronic conditions. Health spending now comprises 18% of our nation’s GDP, by far the largest share in the world. Our spending continues to grow even as our health declines.

The burden of the crisis is heaviest for those who have chronic diseases. People with chronic conditions are disadvantaged in the health care system relative to people with acute conditions. Much of the disadvantage is unintentional – artifacts of policies or practices that predate the rise of chronic conditions.

For example, an increasing number of people have health insurance plans with high deductibles that must be met each year before coverage kicks in. People with chronic diseases who have ongoing costs -- often medications designed to manage those conditions, such as anti-hypertensives, statins, or insulin -- are likely to run through their deductibles every year. By contrast, someone who has an acute medical episode, even if the associated costs are very high, is likely to face the financial burden of his or her deductible at the time of the episode, but will not experience those costs every year.

Until recently, people with chronic diseases faced the likelihood of being denied health insurance coverage altogether or paying significantly higher insurance premiums if they could obtain coverage. Pre-existing condition exclusions and rating on the basis of health status were routine, particularly in the individual and small group health insurance markets. These practices were abolished by the *Patient Protection and Affordable Care Act (ACA)*, but

recently regulatory action by the Trump Administration will expand the availability of health plans not subject to these rules. How many people will purchase these plans, how well they will meet the needs of people with chronic conditions, and how the expansion of this less-regulated market will affect prices for people seeking to purchase comprehensive coverage, is not yet known.

Health insurance typically covers needed services when recovering from an acute illness. Medicare, for example, pays for rehabilitation and home health care after hospitalization (for a knee replacement, stroke, or heart attack, for example). By contrast, the ongoing needs of someone coping with the challenges associated with diabetes or depression are rarely covered by insurance.

- **We are more willing to spend resources to treat chronic conditions than we are to prevent them.**

An ounce of prevention may be worth a pound of cure, but, through our actions, we show more willingness to buy pounds than ounces.



Our orientation toward treating disease rather than preventing it manifests itself in many ways. Health insurance covers all manner of treatment but does not cover forms of primary prevention that address behaviors such as healthy eating or physical activity. Insurance does not typically “reimburse” for non-medical interventions that reduce the likelihood a person will become ill, while payment for medical interventions to

treat preventable conditions is the norm. This has yielded tremendous progress in the treatment of chronic conditions, with much less progress when it comes to advancing our understanding of effective primary prevention.

Under the ACA, most health plans must now cover certain screening services (secondary prevention) such as mammography and colonoscopy. Prior to the ACA, such coverage was not typical. Health insurance typically covers pharmaceuticals that help people prevent their chronic conditions from worsening (tertiary prevention), but cost sharing for medications that must be taken regularly can add up and become a barrier to access.

We cannot treat our way out of the burden of chronic diseases. Not only are many treatments quite expensive, and some have undesirable side effects, but they also reduce, rather than eliminate, the health risks associated with chronic conditions. Worse yet, there are often undesirable interaction effects associated with simultaneous treatment of multiple conditions.

The focus of health systems and health system spending on acute conditions has, not surprisingly, led to increased investment in treatment of acute conditions, often with dramatically positive results. As Dana Goldman and colleagues explain, however, this orientation leads to a systematic underinvestment in approaches to reduce the incidence of chronic disease. To put it differently, the orientation of the health system toward acute care, and the funds that flow toward treatment of acute disease, perpetuate our failure to tackle the growing problem of chronic diseases.

Despite the general orientation of the health care system toward treatment, there are notable efforts to shift that orientation toward prevention. The Diabetes Prevention Plan benefit was added to Medicare in 2018, but it is one of the few non-medical interventions that is currently covered. A similar benefit is now being adopted by some private insurers and Medicaid programs.

Another promising step in reorienting the health system to prevention and wellness is the concept of accountable care. In this model, the health care provider keeps a share of the savings it generates if the cost of serving a defined population ends up lower than expected. Such a model creates financial incentives for investments in prevention, although the relatively short time horizon of most accountable care models may limit that incentive. Medicare has adopted a variety of accountable care models; they are proliferating among private insurers and Medicaid programs as well.

It may seem uncontroversial to say that prevention is preferable to treatment. But most of our payment systems reflect the opposite view. If we are serious about reducing the health and financial burdens of chronic diseases, we must reorient our investments toward prevention.

- **Reducing the burden of chronic disease must begin with tackling obesity.**

We entered into our discussions focused on the growing prevalence and burden of chronic diseases – a gradual shift that many Americans are aware of through their own experiences or through media reports. As we learned more about the topic we came to realize the central role obesity plays in this national crisis.

The Centers for Disease Control and Prevention defines a chronic disease as one that lasts more than one year and that requires ongoing medical treatment or limits daily activities. By that definition, there are many chronic conditions, and they vary in their origins. Yet, obesity stands out as the root of the fastest growing chronic conditions. Of the ten chronic conditions Ken Thorpe examines, eight of them are positively correlated with obesity. The breadth of conditions correlated with obesity is striking – not just diabetes and hypertension, but arthritis and mental health conditions as well.

Even more dramatic than the association between obesity and individual chronic conditions is its association with the most commonly co-occurring conditions. Obesity brings with it elevated risk for a collection of chronic conditions -- diabetes, hypertension, heart disease -- and people with multiple chronic conditions bear a tremendous health burden and drive the largest share of health care costs.

The correlation between obesity and certain diseases does not prove causation. But the clinical evidence for causation is overwhelming. The etiologies of the fastest growing chronic diseases involve pathways rooted in obesity.

Among children ages 2-19, obesity prevalence was nearly 19% in 2015-2016, according to the Centers for Disease Control and Prevention. Our children are at grave risk of living shorter, less healthy lives. Based on the evidence presented to us, we conclude that the single most consequential step the nation could take to reduce the burden of chronic diseases is to reduce the incidence of obesity.

- **The growth in chronic conditions, and the obesity that underlies that growth, arises from multiple causes and systems that need to engage in the solution.**

The burden of chronic disease falls disproportionately on those with lower incomes, education, and who are racial and/or ethnic minorities. Those populations are disproportionately burdened by various challenges, including:

- > underinvestment in basic infrastructure, such as transportation options and safe public spaces
- > the proliferation of unhealthy food options
- > a reduction in physical activity among the population
- > an inadequate mental health system, and
- > the accumulated burdens of stress, including those associated with exposure to violence and the experience of racism

The health care sector did not create the obesity crisis, but it has not responded to it as rapidly as is needed, and it has a unique role to play in responding.

Five Big Ideas to Reduce the Burden of Chronic Disease

There is much we can do to reduce the burden of chronic disease in the United States. The Aspen Health Strategy Group offers five big ideas that will help catalyze this change.

1. Launch a national initiative against obesity.

The nation's leaders should launch an urgent, sustained, multi-sector national initiative to dramatically reduce obesity akin to previous efforts to reduce tobacco usage and increase seat belt usage. In our work, it quickly became clear that obesity is the primary driver of our chronic disease crisis. The health burden of obesity is so profound that a sustained, high-profile campaign is required.

Obesity arises from a combination of genetic makeup and behaviors including food consumption and limited physical activity. Individual behaviors occur in the context of the choices available to people, the information they have, and the resulting choices they make. Children's ability to make healthy choices may be particularly constrained due to neighborhood, school, and family circumstances. And there is growing evidence that behaviors that appear to be choices are actually shaped by environmental factors including stress, exposure to adverse events, and environmental toxins that reshape how people make decisions.



The government's appropriate role in achieving behavior change is always a matter of debate. Governments at all levels, along with various private sector actors, have initiated and supported a number of efforts to reduce obesity. We acknowledge the efforts of former First Lady Michelle Obama in her Let's Move! initiative as well as the Robert Wood Johnson Foundation's sizeable investment in preventing childhood obesity. These efforts have shown some positive results, but they must be sustained and expanded upon to generate the scale of change that is needed.

With these views in mind, we support a national initiative against obesity with the following elements:

- The initiative must have highly credible, non-partisan leadership.
- The initiative must be sustained over an extended period -- most likely decades -- to build new social norms and to allow time for policy experimentation and evolution.
- The initiative must take a systems approach to individual behavior. It cannot simply be an admonition for people to live healthier lives and make healthier choices. It must address the social context in which people make those choices, giving them better options and addressing the economic and cultural barriers to making healthy choices.
- The initiative must address both sides of the healthy weight equation: food and activity.
- The initiative must have a significant education component, helping people, and especially children, understand the relationship between their present-day decisions and their ability to live a healthy life into the future.
- The initiative must be evidence-based, both in the techniques it uses to effect cultural change, drawing lessons from previous campaigns, and in the relationships among food, activity, obesity, and chronic diseases.

2. Promote healthy eating.

The US Government should use the broad array of tools available to it to increase the affordability and availability of healthy foods relative to less healthy foods with the goal of reducing obesity. These tools include taxes, subsidies, education, and a range of programs that provide food to needy families.

Myriad policy choices in multiple domains affect the affordability and availability of different types of foods. A thorough review of these policies should be undertaken. The following topics should be considered as a starting point:

- taxes on products with added sugar and/or sweetened beverages
- agricultural subsidies that affect the price of various commodities
- nutritional guidelines that encourage people to consume various types of food
- food labels that provide information people use to guide their food choices

- food commodities programs that provide foods directly to seniors and schools
- support for markets that provide access to fresh fruits and vegetables
- school meals programs that deliver free and subsidized meals to students
- school policies regarding on-site sales of food and beverages
- policies regarding advertising that promotes the sale of unhealthy foods
- the Supplemental Nutrition Assistance Program (SNAP) that provides funds for people to purchase their own foods



3. Bring all sectors to the table.

The choices people make that lead to obesity arise from myriad policies and behaviors in multiple sectors. These sectors must participate in a comprehensive effort to reduce obesity. Some of the most critical sectors and their roles are:

- The planning and housing communities play a central role in creating the physical infrastructure that can either support or impede healthy behaviors. Communities support healthy habits when people can walk safely to schools, parks, and other community resources. Zoning and related policies affect the availability of fresh foods and the proliferation, or lack thereof, of outlets that primarily sell unhealthy foods. Transportation options play a central role in giving people the time and ability to purchase and prepare healthy foods. Other environmental factors, such as pollution and noise, affect stress and overall wellbeing that are tied to obesity.
- The agricultural sector produces food in accordance with market dynamics and regulations that determine the profitability and viability of producing certain foods. Changes in these policies have the potential to disrupt an important sector of the economy. The creativity of that sector is needed to develop alternative models that produce healthier foods

while assuring the viability of the agricultural enterprise. A possible model for this engagement is a set of policies that yielded a significant reduction in US tobacco production.

- Policies and practices at schools have a significant effect on children's healthy behaviors. Schools affect children through the food they serve and the options offered in vending machines and concessions. School policies affect how much physical activity children engage in during the school day, in after-school activities, and in how they get to school.
- Employers play a similar role for adults. Employer choices about where they locate, the food they serve, and opportunities for physical activity directly affect employees. These employees then bring those habits home and to their own communities, yielding a ripple effect that reaches children and other adults.
- The health care sector has a direct role in improving eating habits. Institutions, particularly hospitals and nursing homes, make choices regarding the food provided to their patients and residents. Work schedules and on-site cafeterias also affect the eating options for clinical and non-clinical staff.
- The media affects people's food choices in both its programming content and advertising. Major social shifts regarding smoking and alcohol consumption have occurred in the context of significant changes in programming and advertising around these two topics. Similar shifts may be necessary to yield changes in food consumption patterns.

4. Reorient health system financing to reward prevention.

Public and private health insurance programs need to be redesigned to promote obesity-prevention initiatives. Health insurance, with its risk pooling function, is an ideal place for investment in prevention. The combination of an empowered individual and a motivated health sector would make a real difference in achieving health improvement goals.

We are currently missing many opportunities to build incentives for prevention into insurance programs and our health care financing models. Such incentives could serve as the foundation for unleashing creativity and investment that would yield substantial health improvement. An effective redesign to promote prevention would explore the following options:

- Medicaid, as the largest source of coverage in the nation for pregnant women and children, should build upon the inclusion of children’s weight assessment as a core quality measure to require states, health insurers, and providers to incorporate obesity reduction as a goal.

5. National commitment to support community-based efforts.

The obesity crisis arises from individual behaviors that are framed and made in a social, economic, and cultural context. While state and national policy can and should be deployed to address this crisis, sustainable progress will require engagement at the community level to provide better options and support people in their choices.

The correlation between social and economic disadvantage and obesity, along with the growing understanding of epigenetics, suggests that community-level efforts must include investments that strengthen opportunities and bring resources to historically disadvantaged communities. A national commitment to support community-based efforts should include the following elements:



- Bring public and private investments into communities that help people meet their basic needs of education, employment, housing, food, recreation, and safety and provide them with economic opportunity.
- Prohibit targeting of disadvantaged communities by certain businesses that profit from promoting unhealthy behaviors, such as tobacco and alcohol use, or actions that cause environmental or financial harm to residents.
- Support community efforts to identify racism, whether current, historical or structural (policies embedded in social and political systems that create racial inequities regardless of intent), and reverse its effects in a way that empowers people to overcome barriers to health.

Moving Forward

Growing obesity rates are a demographic time bomb that is slowly exploding with devastating effect for the people affected and for the country as a whole. The Aspen Health Strategy Group, with its multi-sector membership, has developed these ideas to address the crisis of rapidly growing rates of chronic disease. We hope they will serve as catalysts for changes in policy and practice.

We will take our call for a multi-sector response to those we mention in this report. With our focus on health care, we will share this report with officials in the US Department of Health and Human Services, which houses the Centers for Medicare and Medicaid Services, the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, and other relevant agencies. We will also reach out to other sectors, particularly agriculture and education, both of which have a significant role to play in responding to this crisis.

The Aspen Health Strategy Group members have also committed to examining steps we can take within our own institutions and organizations. We look forward to working with all who share our goal of reducing the burden of chronic diseases.

BACKGROUND PAPERS

Understanding and Preventing Chronic Disease

Kenneth E. Thorpe, Ph.D.

Investing in Prevention to Address the Burden of Chronic Disease and Mental Health

Dana P. Goldman, Ph.D., Seth A. Seabury, Ph.D.,
and Sarah Brandon

Models to Prevent Chronic Disease and Create Health in Communities

Vincent Lafronza, Ed.D., M.S.,
and Lisa Tobe, M.P.H., M.F.A.

Ethical Issues in Responding to Chronic Diseases

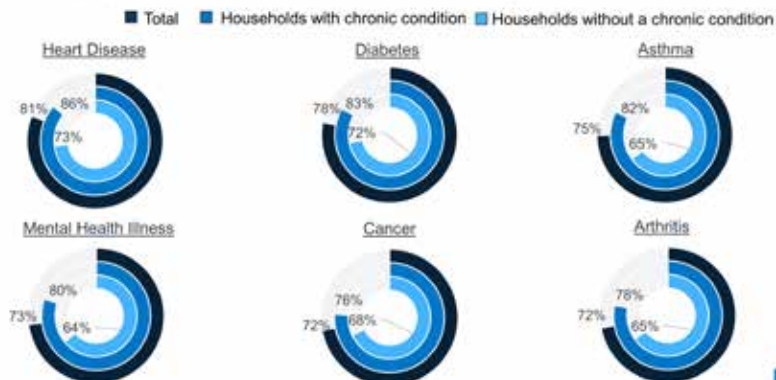
Barbara K. Redman, Ph.D., M.B.E.

Part 2



Most Americans Are Aware of What Constitutes a Chronic Disease, But Gaps Exist

Percent who say they think the term "chronic disease" applies to each of the following:

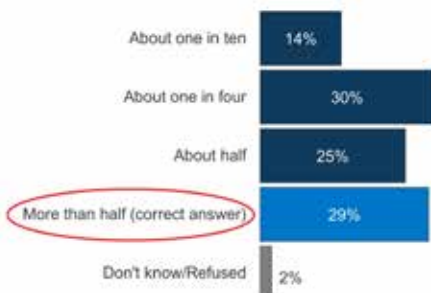


NOTE: Items asked of separate half samples.
SOURCE: KFF Health Tracking Poll (conducted April 20-30, 2018)

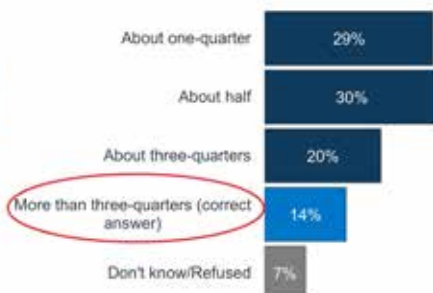
KFF
Kaiser Family Foundation
HEALTH TRACKING POLL

Most of the Public Are Unaware of Scope of Chronic Disease Challenge in the United States

How many individuals do you think live with a chronic disease in the U.S.?



About how much of all money spent on health care in the U.S. is spent treating chronic disease?



NOTE: Questions asked of separate half samples.
SOURCE: KFF Health Tracking Poll (conducted April 20-30, 2018)

KFF
Kaiser Family Foundation
HEALTH TRACKING POLL

“The persistent rise in obesity, particularly among adults, is a key driver of certain chronic diseases such as diabetes, hypertension and stroke.”

– KENNETH E. THORPE, PH.D.

Understanding and Preventing Chronic Disease

Kenneth E. Thorpe, Ph.D.

Chronic diseases are the leading causes of death and disability in the US (CDC, About Chronic Diseases, 2018). Seven of the top ten causes of death are due to chronic diseases including heart disease, cancer, chronic respiratory disease, stroke, Alzheimer's, diabetes and chronic liver disease (CDC, 2017). They also account for the vast majority of health care spending. The costs of treating chronic disease account for more than 86% of health care spending (author tabulation from the Medical Expenditure Panel Survey (MEPS)). This paper examines the epidemiology of chronic diseases, including who they affect and key risk factors. The paper also examines tools and reforms that would assist in more effective prevention, detection and management of chronic disease.

The Importance of Chronic Disease in our Health Care System

According to the US National Center for Health Statistics, chronic diseases are conditions that are expected to last at least three months, although most of these conditions last considerably longer (MedicineNet, 2016). Chronic diseases include conditions such as heart disease, cancer, diabetes, hypertension, and arthritis, among several others. My tabulations from the 2015 Medical Expenditure Panel Survey (MEPS) show that patients with chronic disease account for 86% of total health care spending. In contrast, patients with chronic disease accounted for only two-thirds of total health care spending in 1990. Today, two-thirds of adults have at least one chronic health care condition (author's tabulation from the 2015 MEPS).

This paper examines the factors that underlie the rising prevalence of chronic diseases and the role they assume in the growth in health care spending. Several factors, most of which are outside the traditional health care system, affect chronic disease prevalence, morbidity and mortality rates. These determinants

of health include environmental factors, socio-economic status, transportation, genetics, lifestyle and behavioral factors, social services and education. In addition, the paper outlines potential policy changes that could slow, or even reduce, the rising prevalence of chronic disease and that have the potential to reduce the rate of growth in health care spending. Given the underlying causes of morbidity and chronic disease, these solutions will require interventions that include not only health care, but also a much broader policy framework.

Chronic Disease Prevalence and Trends

This section focuses on the prevalence of treated chronic disease. Treated prevalence only includes patients who have been diagnosed with a disease and have received medical treatment for that disease. Treated prevalence understates overall disease prevalence as some disease goes undiagnosed, untreated and unreported. The most prevalent chronic conditions among adults in 2015 were hypertension (26%), hyperlipidemia (20%), mental disorders and arthritis (17%) and diabetes (11%). For most of these conditions, at least two-thirds of those with the chronic condition were overweight or obese. Among patients with heart disease, pulmonary disease, diabetes, hypertension and hyperlipidemia, approximately three-quarters were either overweight or obese (Exhibit 1).

Older patients were the most likely patients to have these common chronic health care conditions. In all ten of the conditions examined, adults aged 65 and older accounted for the plurality of patients, and those under age 35 accounted for the least. Of note, nearly 60% of patients with heart disease and cancer were over age 65.

EXHIBIT 1. PREVALENCE OF MOST EXPENSIVE CHRONIC CONDITIONS AND RISK FACTOR CHARACTERISTICS, ADULTS 18+, 2015

Condition	Prevalence	Normal Weight	Risk Factors				Age			
			Over-weight	Obese	Smoker	18-34	35-54	55-64	65+	
Heart Disease	9.9%	24.2%	34.4%	39.7%	12.8%	4.6%	15.9%	20.3%	59.1%	
Cancer	6.8%	32.4%	36.8%	28.9%	8.5%	3.4%	17.0%	23.2%	56.4%	
Pulmonary Disease	12.8%	26.6%	32.9%	38.7%	16.2%	17.1%	27.3%	20.5%	35.1%	
Mental Disorders	17.4%	29.0%	30.7%	38.2%	21.5%	23.3%	31.2%	21.6%	23.9%	
Arthritis	16.5%	24.1%	32.2%	42.0%	15.8%	8.6%	26.2%	25.2%	40.0%	
Hyperlipidemia	19.9%	21.0%	36.0%	42.2%	12.9%	15.6%	21.0%	27.6%	49.8%	
Hypertension	26.1%	19.2%	33.8%	46.1%	13.9%	3.4%	23.8%	25.8%	47.0%	
Back Problems	10.0%	26.6%	33.4%	38.6%	16.7%	15.4%	34.0%	22.7%	27.9%	
Diabetes	10.7%	14.1%	31.3%	54.2%	12.8%	4.0%	24.9%	25.6%	45.5%	
Cerebrovascular Disease	1.4%	28.8%	36.2%	34.0%	14.2%	0.9%	12.6%	21.9%	64.7%	

Source: Author's tabulations from the Medical Expenditure Panel Survey (MEPS)

As of 2015, approximately 65% of adults had at least one chronic health care condition (Exhibit 2). Among Medicare beneficiaries, nearly 94% have one or more chronic health care condition. Perhaps the most remarkable trend is the growth in the number of patients with multiple chronic conditions. Both the prevalence of chronic disease and the number of patients with multiple chronic conditions have increased sharply over time. In 1996, 8% of adults were treated for five or more chronic health care conditions. By 2015, 18% of adults were treated for five or more chronic health care conditions. Adults with five or more chronic health care conditions accounted for 31% of total health care spending in 1996, compared to 53% in 2015.

EXHIBIT 2. DISTRIBUTION OF ADULTS AND SPENDING BY NUMBER OF CHRONIC CONDITIONS. 1996 - 2015

All Adults				
Number of Chronic Conditions	% All Adults		% Total Spending	
	1996	2015	1996	2015
0	39.4%	34.9%	9.3%	5.3%
1	23.3%	18.7%	19.0%	10.0%
2	14.6%	12.2%	15.7%	10.2%
3	8.9%	9.2%	13.1%	10.0%
4	5.7%	7.0%	12.1%	11.9%
5+	8.1%	17.9%	30.7%	52.5%

Source: Author's tabulations from the Medical Expenditure Panel Survey (MEPS)

Medicare patients with multiple chronic conditions assumed an even larger role in overall spending and prevalence (Exhibit 3). Approximately one-quarter of Medicare enrollees were treated for five or more chronic conditions in 1996, compared to 52% in 2015. Medicare patients with multiple chronic conditions accounted for a large share of the growth in program spending. In 1996, Medicare patients with five or more chronic conditions accounted for more than half of total Medicare spending. By 2015, these clinically complicated patients accounted for three-quarters of Medicare spending.

Recent analyses by the Partnership to Fight Chronic Disease highlight the enormous cost of chronic disease on the medical care system as well as reductions in workplace productivity. (Partnership to Fight Chronic Disease, 2017). As of 2016, chronic disease accounted for over \$2 trillion in health care spending per year and another \$794 billion in lost productivity. The Partnership projections indicate that between 2016 and 2030 the total cost of chronic disease will sum to \$42 trillion in health care spending and lost productivity. These figures highlight a central health policy challenge we face in preventing and managing patients with chronic disease.

EXHIBIT 3. DISTRIBUTION OF MEDICARE SPENDING BY NUMBER OF CHRONIC CONDITIONS. 1996 - 2015

Medicare				
Number of Chronic Conditions	% Medicare Patients		% Total Spending	
	1996	2015	1996	2015
0	10.9%	6.3%	1.1%	1.0%
1	15.4%	7.0%	6.9%	2.0%
2	17.7%	9.8%	10.7%	4.7%
3	16.2%	11.8%	12.1%	6.4%
4	13.6%	13.5%	17.0%	10.7%
5+	26.4%	51.5%	52.2%	75.3%

Source: Author's tabulations from the Medical Expenditure Panel Survey (MEPS)

Rising rates of patients with multiple chronic conditions reflect the persistent rise in obesity (discussed below) and the growth in conditions that are likely to coexist with other chronic conditions. Diabetes prevalence has increased by eight percentage points since 2003. There is a positive association of diabetes and cardiovascular disease (American Heart Association, 2018). Diabetics are two to four times more likely to die from cardiovascular disease than those without diabetes (American Heart Association, 2018).

Collectively, the prevalence of chronic disease has increased over time, but several conditions account for the bulk of the increase (Exhibit 4). Among Medicare beneficiaries, the prevalence of some chronic diseases has stabilized over time while others continue to rise at a steady pace. For example, the prevalence of heart disease has only increased by 1.7 percentage points since 2003 and the prevalence of cerebrovascular disease (stroke) actually declined over this period. In contrast, the prevalence of three chronic conditions has increased sharply since the early 2000s. Hypertension prevalence increased by 14 percentage points between 2003 and 2015; diabetes prevalence increased by nearly eight percentage points; and mental disorders by over six percentage points. Factors accounting for these trends are discussed below.

EXHIBIT 4. TREATED CHRONIC DISEASE PREVALENCE, 2003 - 2015

Condition	2003	2015	Percentage Point Change
Heart Disease	26.9%	28.6%	1.7%
Cancer	13.4%	17.7%	4.3%
Mental Health	19.1%	25.4%	6.3%
Pulmonary Disease	20.9%	23.3%	2.4%
Asthma	4.8%	7.5%	2.7%
Diabetes	16.8%	24.7%	7.9%
Hypertension	45.8%	59.4%	14.1%
Stroke	4.3%	4.2%	-0.1%
Hyperlipidemia	23%	47.5%	24.5%
Arthritis	25.6%	34.1%	8.5%

Source: Author's tabulations from the Medical Expenditure Panel Survey (MEPS)

Risk Factors for Chronic Disease

In addition to population aging, several factors are associated with poor health outcomes and chronic disease. Behaviors such as lack of physical activity, excess body fat, poor diet and sedentary behavior are all associated with excess weight gain resulting in patients who are overweight or obese. Tobacco use and excess alcohol consumption are also key risk factors. Smokers have elevated risk of cardiovascular disease, stroke and lung cancers (CDC, Trends in Cigarette Smoking, 2017). The Centers for Disease Control and Prevention (CDC) estimates that avoiding tobacco, healthier eating, increasing physical activity, and reducing the prevalence of obesity could prevent 80% of heart disease, stroke, type 2 diabetes and hypertension and 40% of certain forms of cancer.

These risk factors vary by education and income, race and ethnicity and region of the country (Exhibit 5). College graduates are far less likely to smoke or be obese. Fewer than 6% of college graduates are current smokers compared to 20% of adults who only graduated from high school or did not complete high school. Fewer than a quarter of college graduates are obese compared to 35% of adults who graduated from high school or had some college education.

These risk factors vary by income as well. Fewer than 10% of adults in households with incomes above four times the poverty level smoke, compared to more than 27% of adults living in poverty. Similar, though less pronounced, dif-

EXHIBIT 5. CHRONIC DISEASE RISK FACTORS BY KEY DEMOGRAPHICS

	% Smokers	% Obese
Total	15.2%	32.0%
Education		
Less than high school	19.5%	30.2%
HS Grad	22.3%	35.7%
Some College	15.8%	35.4%
College	5.6%	23.9%
Poverty (% Federal Poverty Level)		
<100%	27.8%	33.8%
100-199%	20.3%	33.1%
200-399	16.0%	33.6%
400%+	9.2%	28.5%
Race/Ethnicity		
Hispanic	9.1%	34.4%
NH white	16.2%	30.5%
NH black	19.6%	41.5%
NH Asian	7.5%	8.7%
NH other	20.4%	36.0%
Region		
Northeast	15.3%	27.8%
Midwest	18.2%	34.1%
South	16.1%	34.5%
West	10.7%	26.4%
Source: Author's tabulations from the 2015 Medical Expenditure Panel Survey (MEPS)		

ferences were found by income among obese adults. Risk factors also differed by race and ethnicity. Non-Hispanic Asians were the least likely to smoke or be obese. Non-Hispanic blacks and Hispanics of any race were the most likely to be obese (42% and 34%, respectively).

Finally, risk factors varied geographically as well. More than 34% of adults in the South and Midwest are obese compared to 26% in the West. Adults in the West were also least likely to smoke, with 11% of adults as current smokers compared to 18% in the Midwest.

Trends in Risk Factors

Trends for these risk factors are moving in different directions. Tobacco and cigarette use have fallen over time but remain high. Smoking rates among adults have fallen in half from 33% in 1980 to 17% today. Overall mortality rates are three times higher for smokers than non-smokers. Smoking is linked to lung and other cancers, pulmonary disease, and cardiovascular disease (CDC, Health Effects of Cigarette Smoking, 2017). More than 480,000 deaths each year are associated with smoking.

At the other extreme, one set of risk factors, inactivity, poor diet and obesity, are moving in the opposite direction. The persistent rise in obesity, particularly among adults, is a key driver of certain chronic diseases such as diabetes, hypertension and stroke. In 1988, approximately 15% of adults ages 20 to 74 were obese. Today, nearly 40% of the adult population is considered obese (CDC, Prevalence of Obesity, 2017). Obesity is a strong risk factor for type 2 diabetes, hypertension and hyperlipidemia. The rising prevalence of obesity is linked to rising chronic disease prevalence and higher health care spending. Overall, the rise in obesity and changes in the intensity of treatment account for 20% to 30% of the growth in health care spending since 1987 (Thorpe and Philyaw, 2012).

Relationship between Risk Factors and Chronic Disease

I examined the correlation of these behavioral risk factors with the likelihood of having a chronic condition. These results largely mirror the demographics of the risk factors outlined above. The results are presented below (Exhibit 6). The likelihood of having a chronic disease increases substantially with age and by key risk factors such as lack of regular physical exercise and overweight and obesity. Overweight and obese adults are 1.2 and 1.7 times, respectively, more likely to have heart disease than a normal weight adult. In addition, adults who exercise are approximately 40% less likely to have heart disease compared to those who do not exercise.

The prevalence of heart disease also increases sharply with age. Adults ages 36 to 54 were three times more likely to have heart disease than those under age 36. Similarly, adults ages 55 to 64 and those over age 65 are 7.7 and 25 times, respectively, more likely to have heart disease compared to those under age 36. Smokers were 10% more likely to have heart disease than non-smokers.

Similar results were observed for adults with mental disorders, arthritis, hyperlipidemia, hypertension, back problems and diabetes. In the case of diabetes,

EXHIBIT 6. LIKELIHOOD OF HAVING A CHRONIC DISEASE BY KEY RISK FACTORS, 2015

Condition	Risk Factor									
	Heart Disease	Cancer	Pulmonary	Mental Health	Arthritis	Lipid	High Blood Pressure	Back Pain	Diabetes	Cerebrovascular Disease
NH Black	0.92	0.43	0.72	0.37	0.99	0.69	1.60	0.70	1.55	1.56
NH Other	0.71	0.44	0.72	0.39	0.88	1.01	1.08	0.69	1.78	0.97
Hispanic	0.57	0.42	0.66	0.42	0.79	0.71	0.73	0.54	1.60	1.02
Age 36-54	3.05	4.98	1.48	1.22	2.95	12.60	7.09	2.11	5.47	13.21
Age 55-64	7.73	12.93	2.19	1.63	6.22	41.13	21.18	2.66	12.79	46.05
Age 65+	25.05	28.25	3.57	1.53	10.10	94.16	63.78	2.85	25.56	121.33
Underweight	1.10	1.02	1.29	1.40	1.33	0.53	0.75	0.97	0.46	0.49
Overweight	1.22	0.92	1.12	0.98	1.15	1.67	1.81	1.13	1.98	0.96
Obese	1.68	0.81	1.51	1.39	1.82	2.61	4.03	1.43	4.42	0.96
Smoker	1.11	0.62	1.23	1.77	1.30	1.10	1.15	1.20	1.09	1.26
Exercise	0.63	0.92	0.77	0.62	0.71	0.76	0.72	0.83	0.64	0.51
_cons	0.02	0.01	0.08	0.22	0.05	0.01	0.02	0.06	0.01	0.00

Source: Author's tabulations from the Medical Expenditure Panel Survey (MEPS)

adults ages 36 to 54, 55 to 64, and over 65, were 5.5, 12.8 and 25 times, respectively, more likely to have diabetes than those under age 65. Overweight and obese adults were twice as likely and more than 4.4 times more likely, respectively, to be diabetic than normal weight adults. Adults who exercise are nearly 40% less likely to have diabetes compared to those who do not exercise.

These key risk factors and cancer had a different association. Cancer prevalence also increases with age. Those 36 to 54, 55 to 64, and over 65, were 5, 13 and 28 times, respectively, more likely to have cancer than those under age 36. However, obese adults and smokers were less likely to have cancer than nonsmokers and normal weight adults. This association could simply reflect the impact that cancer has on weight and weight loss. Similar results were observed for adults with a cerebrovascular event. Adults who exercise were half as likely to have had a stroke compared to those that do not. The prevalence of stroke also increased dramatically with age. However, overweight and obese adults are as likely as normal weight adults to have had a stroke.

There are also significant differences in chronic disease prevalence by race and ethnicity. This is particularly the case for conditions related to excess weight such as diabetes, hypertension, and stroke. This may be associated with the substantial differences in obesity prevalence by race (CDC, 2015). In 2014, 34.5% of non-Hispanic whites were obese compared to more than 48% among non-Hispanic blacks and 43% among Hispanics of any race. For instance, non-Hispanic



blacks are 55% more likely to be diabetic, 60% more likely to have high blood pressure and 56% more likely to have cerebrovascular disease than non-Hispanic whites (Exhibit 6). However, racial minorities are less likely to have cancer, pulmonary disease, or report mental health problems compared to non-Hispanic whites.

Other behavioral risk factors have declined over time leading to lower rates of chronic disease and increased longevity. Most prominent is the reduction in smoking prevalence. These trends have led to lower rates of pulmonary disease, cancers, heart disease and stroke compared to what they would have been had smoking rates not declined.

In addition to the increase in clinical incidence and prevalence of chronic disease associated with rising obesity rates, other factors within our health care system may also increase chronic disease. Unlike the rise in chronic disease associated with lifestyle and behavior, some of the rise in prevalence may actually be desirable. Changing clinical thresholds for treating patients associated with new information from clinical trials may result in more patients treated (increasing the prevalence of treated disease) for conditions like hypertension and hyperlipidemia. This more aggressive approach to treatment may result in fewer cases of heart disease and stroke (Cutler, et al., 2007). Treatment guidelines have also changed for other conditions including asthma and diabetes. Treatment guidelines through the late 1990s recommended that hemoglobin A1c levels should remain below 7%. These guidelines were changed to 6.5% in 2001 resulting in a broader pool of potential diabetic patients and an increase in treated prevalence (Thorpe and Philyaw, 2012). In addition, broader use of clinical preventive services has increased the detection (and thus treated prevalence) of chronic disease. One example is diabetes. Today, over three-quarters of diabetics (23 million) have been diagnosed, while 25% have not been diagnosed and treated (CDC, National Diabetes Statistics Report, 2017). In contrast, in 1990 only 63% of diabetics were diagnosed (4.7 million) with 2.8 million undiagnosed (Gregg, et al., 2004).

As discussed earlier, longer life expectancy increases the likelihood of having one or more chronic health care conditions. This occurs since the prevalence of chronic disease increases sharply with age. Adults over age 65 are 25 times more likely to have heart disease and 28 times more likely to have cancers compared to adults under age 36.

New medical treatments have also increased the prevalence of chronic disease. Until the development of selective serotonin reuptake inhibitors (SSRIs), non-medical counseling was the primary source of treatment for depression. Thus, depression was not treated through medications or medical treatment and, as a result, there was no treated medical prevalence.

Opportunities for Prevention

Chronic diseases have assumed a growing role in overall health care spending and morbidity. Of special concern is the persistent growth in type 2 diabetes and cardiovascular diseases related to diet, exercise and nutrition. Crafting effective solutions to reducing the growth in these key chronic diseases and keeping patients with multiple chronic conditions healthy will require an approach that is patient focused and relies on multiple policy tools and interventions. This section outlines health policy opportunities that could effectively reduce the growth in behavioral risk factors like obesity and, with it, chronic disease. In addition, population-based health programs that integrate social, health care, and other determinants of health could represent the next generation of approaches to reducing the burden of chronic disease.

Primary Prevention

Primary prevention focuses on preventing the onset of disease. To be effective, primary prevention needs to use evidence-based interventions that reduce the key chronic disease risk factors such as diet, lack of physical activity, obesity, smoking and excess drinking. To make a noticeable difference in the incidence of disease, these strategies must be easy to scale nationally.

Fortunately, interventions exist that promote weight loss and other behavior changes and result in a reduction in chronic disease incidence. One such intensive lifestyle modification program is the Diabetes Prevention Program. The Diabetes Prevention Program (DPP) provides 12 months of core sessions (and an additional 12 months of maintenance sessions) that focus on tools to change behavior and diet, and target 150 minutes of physical activity per week (Alva, et al., 2017). Overweight and obese adults that are prediabetic are eligible for

the new DPP benefit in Medicare. The goal of the program is to get participants to lose 5% or more of their bodyweight. Studies have demonstrated that the program reduces the incidence of diabetes by 58% and results in savings of approximately \$2,650 per enrollee over a 15-month period (Alva, et al., 2017).

The DPP was added to the Medicare benefit package in April 2018 as an important new prevention benefit. The potential that the DPP has to reduce chronic disease incidence and lower costs is substantial as an estimated 23 million seniors are prediabetic and more than 84 million adults are prediabetic (CDC, National Diabetes Statistics Report, 2017).



Two key implementation challenges face the roll out of the DPP. The first challenge is developing the capacity to provide the benefit nationally. Organizations that wish to be a DPP provider and bill Medicare for the service must be certified by the CDC.

Under the rules established by the Centers for Medicare & Medicaid Services (CMS), the federal agency that runs Medicare, “virtual” or internet-based providers are not eligible to provide the benefit. Rather, they are limited to providing no more than two make-up sessions for missed classes. Certified providers must require beneficiaries to attend classes in person. Absent these virtual providers, the national availability of the program in the near term for Medicare and other patients may be in question (CDC, CDC Recognition, 2018).

A second challenge is getting eligible beneficiaries enrolled in and completing the program. Beneficiaries must be made aware of their eligibility, and then be assisted by a physician or other organization to find an eligible program. One emerging approach involves organizations (e.g., Solera Health) to match eligible patients with certified DPP providers. CMS may have to adopt additional methods to ensure Medicare beneficiaries are aware of the new program and their eligibility for the benefit.

Secondary Prevention

Secondary prevention is designed to lead to early diagnosis of a disease and earlier treatment. A good start to increasing secondary prevention was included as part of the *Patient Protection and Affordable Care Act* (ACA, 2010) (Section 2713). Under this section, most private and public health plans must cover the full cost of

clinical preventive services that the US Preventive Services Task force gives a grade of A or B (there is high certainty that the service results in a moderate (B) or substantial (A) net benefit to patients). Eliminating cost sharing results in higher screening rates (Trivedi, et al., 2018). However, eliminating financial barriers is only part of the overall strategy that is required to increase screening rates. Three additional components would be helpful. First, education on age and gender appropriate screenings should be a core part of any workplace wellness program. Second, the key medical societies could develop strategies or approaches that would integrate screening information into the clinical records in physicians' offices, hospitals and other health care providers. Finally, education, literacy and screening adherence could be a key part of the patient-centered care coordination reforms that are outlined below (CDC, National Diabetes Statistics Report, 2017).



Tertiary Prevention

Tertiary prevention is designed to increase the quality of life among chronically ill and other patients by keeping them healthy and managing or reducing their symptoms. To be successful, these interventions must focus on evidence-based solutions with a clear link to how the interventions will achieve these goals. Given the role that patients with multiple chronic conditions play in our health care system, a successful tertiary prevention model will need to reorient the system toward prevention and focus on patient-centered, team-based care. Moreover, the framework for a successful tertiary care program will have to include not only the health care system but also other elements that impact patient outcomes.

Integrating health and social services in the management of chronically ill patients has been shown to produce better health outcomes at lower costs (Bradley, et al., 2016). This concept builds off of international work that reports better health outcomes in countries that spend substantially less on health care than the United States. This is traced in part to the fact that these largely European

countries, while spending less on health care, spend substantially more on social services than the United States (Commonwealth Fund, 2015). These social service investments are associated with improved health outcomes and lower chronic disease prevalence. Recent studies in the United States have found similar results (Bradley, et al., 2016). Other studies have focused on the role that higher spending on social services (housing, education, transportation, the environment, public safety, income support, and nutrition programs) plays in reducing chronic disease prevalence and improved health outcomes. States with higher ratios of social services to health care spending were associated with lower rates of obesity, asthma, diabetes and mental disorders. These effects were substantial: a 20% increase in the median state level ratio of social to health care spending was associated with a .33 percentage point reduction in obesity – a reduction of approximately 85,000 obese adults (Bradley, et al., 2016).



Community level evaluations have produced similar results (Thorpe and Joski, 2017). This study examined the individual components of social services spending and their association with lower chronic disease prevalence, age adjusted cancer mortality, and total mortality rates. In addition to the impact that behavioral factors have on these community level outcome measures, this study found that higher investments in education per pupil, lower levels of environmental pollutants, increased investments in park and recreation services and public welfare were associated with lower rates of asthma, obesity, poor mental health days, and diabetes, and improvements in age-adjusted cancer and overall mortality rates.

We also have data from several state demonstrations, such as the multi-payer advanced primary care practice demonstration run through the Centers for Medicare & Medicaid Services (CMS, 2017). The evaluations of these demonstrations provide valuable insight into how to design a comprehensive national approach for managing chronically ill patients.

Programs to Promote Prevention

This section outlines short-term and long-term approaches to adopting these evidence-based models and transforming our prevention and care coordination system.

Short-Term Strategies Through Medicare Advantage

Short-term strategies could build on existing programs, such as Medicare Advantage. Medicare Advantage plans provide Medicare and supplemental benefits and are administered by private health insurance plans. This short-term approach would give the plans more flexibility to provide additional health and social benefits to more effectively prevent and manage chronic diseases. Under Medicare Advantage, plans that bid below an established benchmark receive a “rebate” that can be used to provide additional Medicare benefits. Traditionally, these additional benefits have been health care-related, such as reduced cost sharing, and medical benefits, such as vision and dental benefits, not covered by Medicare.

More recently, CMS has broadened the permissible use of rebates for primary health-related benefits that address some of the social determinants of health. The final 2019 Medicare Advantage rule will allow plans to tailor their use of rebates to the population enrolled in their plan. This will allow plans to offer more social services in addition to more traditional health benefits and cost sharing reductions.

In addition, CMS continues to expand its use of value-based insurance design (VBID). In a VBID plan, copayments and deductibles are customized to the value of the service provided. For example, a VBID plan may waive copayments for prescription drugs, such as statins, that maintain the health of people with chronic diseases.

Short-Term Strategies Through Traditional Medicare

Nearly 40 million people -- 65% of Medicare beneficiaries -- are enrolled in the traditional fee-for-service Medicare program (Congressional Budget Office, 2018). Much of this population is clinically complex and expensive. As noted earlier, 62% of those enrolled in traditional Medicare are treated for five or more chronic conditions and account for 85% of Medicare spending.

Despite the high cost and clinical complexity of its beneficiaries, the traditional fee-for-service program does not have a comprehensive approach for coordinating care. While Medicare has added CPT0-4 codes allowing physicians to

provide and bill for care coordination and transitional care, surveys show that few physicians are providing these services. A recent evaluation of the program showed that fewer than 700,000 Medicare patients received care coordination services through 2016 (Schurrer, et al., 2017). The low participation rate may be linked to the fact that physicians have traditionally not designed, created or provided transitional and care coordination services. Moreover, the time involved in administration and documentation requirements over and above their normal workload has proved to be a barrier.



This problem is compounded by the fact that physicians must obtain patient approval each time they bill for these services, since the patient is responsible for 20% of the costs (Schurrer, et al., 2017).

A more comprehensive approach for providing care coordination in the traditional Medicare program would rely on patient-centered community health

teams. Medicare has participated in several state demonstrations using interdisciplinary teams with some success reducing spending and improving outcomes. Moreover, even though participation in the existing chronic care management services is very low, the evaluation of the chronic care services program showed it reduced the growth in Medicare spending among those receiving services (Schurrer, et al., 2017).

Under this framework, community health teams would be responsible for improving population health outcomes in their hospital referral regions. They would provide access to care coordination services for all Medicare patients regardless of income, race, or gender. They could also contract with accountable care organizations (ACOs), health systems, private health plans, Medicare Advantage plans as well as Medicaid programs. In addition to developing the teams, CMS would replicate programs that work collaboratively with the health teams – the Vermont-based Support and Services at Home (SASH) program, for example. The SASH program delivers social and housing services and its service offerings are integrated into the care plan for chronically ill patients (Support and Services at Home, 2018).

Health teams would consist of nurses, nurse practitioners, pharmacists, public health nurses, and behavioral health specialists, among others. The teams would:

- Provide a “whole” person focus on preventing disease and managing acute, chronic and behavioral health services.
- Provide a care coordinator for the patient with medical advice available 24/7.
- Help to implement the patient’s care plan.
- Provide comprehensive medication therapy management.
- Provide health coaching and education as well as transitional care services.
- Have regular contact with the patient and provider to monitor progress in meeting the care plan.
- Use evidence-based health coaching to develop patient self-management skills and facilitate positive lifestyle and behavior changes.
- Use electronic records to track patient outcomes that are linked to the provider practices allowing both the care coordinator and provider to track their patients.

The program would be structured as follows:

- CMS would contract with the teams through a competitive bidding process. Several states already do this as part of their participation in the multi-payer demonstration through the CMS Center for Medicare and Medicaid Innovation (CMMI).
- Team members would be salaried. They would also be paid based on improvements in health at the community level as well as among Medicare patients.
- The prevention and care coordination services would be provided to the patient at no charge.
- Physicians collaborating with the teams would also be paid a per member, per month fee based on the number of patients using care coordination services. Payments would increase with the number of National Committee for Quality Assurance (NCQA) medical home points at the provider practice.
- The teams would be responsible for coordinating existing community resources as well as integrating social service benefits into the care plan (similar to what Vermont has done with its Support and Services at Home program).

- The teams would serve as a primary source for referring patients to the new Diabetes Prevention Program in Medicare. They would also coordinate referrals and links for opioid treatment (hub and spoke model).

Long-Term Strategies

Long-term reforms would build upon the concept of community health teams outlined above. Rather than ACOs as they currently exist, the new delivery models would be Accountable Health Organizations (AHO). The AHO concept would expand the ongoing work initiated by CMS to develop Accountable Health Communities, which exist in 32 communities today (Alley, et al., 2016). According to CMS, these organizations:

- screen community-dwelling beneficiaries to identify certain unmet health-related social needs;
- refer community-dwelling beneficiaries to increase awareness of community services;
- provide navigation services to assist high-risk community-dwelling beneficiaries with accessing community services; and
- encourage alignment between clinical and community services to ensure that community services are available and responsive to the needs of community-dwelling beneficiaries.

The AHO concept goes farther, adding to the role the teams play by integrating behavior change programs, social services, economic and housing programs with team-based health care to assure the effective implementation of a care plan for patients in their community.

These organizations would start with a care plan developed by the patient's primary care physician and then add to it a health-related social needs assessment that complements the care plan. This social needs assessment would identify lifestyle or behavioral issues (including opioid addiction) and social and economic needs, and provide a plan to work with communities on environmental quality issues.

An "integrator" organization, which could be an enhanced community health team, would be responsible for improving or maintaining the health of patients in the community. This hub and spoke model would be funded by Medicare and Medicaid by expanding the Medicaid health homes concept in section 2703 of

the *Affordable Care Act* (ACA, 2010) and any other private plans or ACOs that want to contract with them. Having a health and social needs assessment will allow the team to help implement the broader care plan. The integrator team would work closely with federal, state and local governments in linking patients to:

- low-income energy programs
- SNAP (food stamps) enrollment
- assistance in finding employment
- nutrition education and links to sources for healthy foods
- transportation assistance through Uber, Lyft or others
- working with the Support and Services at Home programs for housing assistance
- referrals to a local diabetes prevention program
- assistance, where feasible, in achieving at least 150 minutes per week of physical activity through links to local parks and recreation, YMCAs or other health club vendors
- referral to an opioid treatment center

Discussion

The shift toward value-based payments provides strong incentives for major delivery system reforms. These reforms could be completed in stages, starting with Medicare Advantage plans continuing to get more flexibility in how they use their rebates. The reforms must prevent the persistent rise in chronic disease and recognize the clinical complexity of patients in the system today. To be effective, the reforms must address the range of factors that affect obesity and chronic disease prevalence.

Team-based care that integrates a care plan for patients with multiple chronic conditions, and linking these patients to community-based prevention, social, housing, and transportation services, could prove to be an effective strategy for improving population health and ultimately reducing the growth in health care spending.

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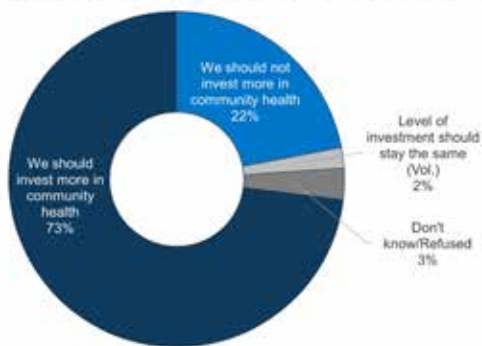
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Most Americans Say Society Should Invest More to Improve Health

As a society, do you think we should invest more in order to improve the health of communities and help people make healthy choices or do you think we should not invest more to improve the health of communities and help people make healthy choices?

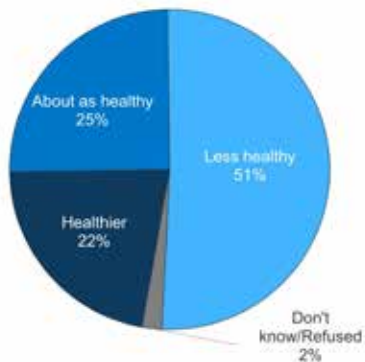


NOTE: Based on registered voters.
SOURCE: Robert Wood Johnson Foundation and Trust for America's Health Survey (conducted September 8-19, 2016)



Many Americans Are Pessimistic About the Trajectory of Health for the Next Generation

Thinking about today's children in this country, when they reach adulthood, do you think their generation will be healthier, less healthy, or about as healthy as adults today?



NOTE: Based on registered voters.
SOURCE: Robert Wood Johnson Foundation and Trust for America's Health Survey (conducted September 8-19, 2016)



“This short-term thinking is endemic to our approach to financing. On the system side, this reflects the short-term nature of insurance contracts. We choose our plans annually, and so we tend to focus on annual spending and use. On the patient side, these contracts reinforce a fundamental problem with health behavior; namely, that we have a hard time internalizing investments that will pay (health) dividends much longer down the road. ”

– DANA P. GOLDMAN, PH.D., SETH A. SEABURY, PH.D.,
and SARAH BRANDON

Investing in Prevention to Address the Burden of Chronic Disease and Mental Health

Dana P. Goldman, Ph.D., Seth A. Seabury, Ph.D., and Sarah Brandon

Introduction

Over the last century, the United States has become very good at keeping people alive through public health activities and medical care. Part of this progress is due to investments early in life; infant mortality has fallen, and life expectancy at birth has increased (Olshansky, et al., 2009). We also have made progress extending life at older ages; fewer people are dying from heart disease, and cancer survival rates are increasing (D. Goldman, 2016). These advances -- when combined with declines in fertility and immigration rates -- increasingly skew the United States toward a society where the fastest growing demographic group is Americans aged 85 to 94 (Werner, 2011).

However, the United States is becoming a victim of its demographic success. While Americans are living longer, they are not necessarily living healthier. Disability rates have been rising, due in large part to the prevalence of major chronic diseases such as high blood pressure, heart disease, diabetes, cancer, and stroke among our elderly (Bhattacharya, et al., 2004); (Lakdawalla, et al., 2004). This trend is fueled in part by lifestyle factors, including rising obesity rates (Lakdawalla, et al., 2004). These factors impact different racial and ethnic groups in disproportionate ways; black Americans experience higher rates of obesity and high blood pressure than the rest of the population, with these disparities playing out especially starkly in middle and older age (Witters and Wood, 2014).

New diseases that were previously rare have emerged as serious killers – most notably Alzheimer’s disease and dementia. As a result, functional status among the elderly is worsening. Recent estimates predict that life expectancy for

65-year-olds will grow by about a year between 2010 and 2030, but expected years of life spent with disability will increase even more (from 7.4 to 8.6 years) (Gaudette, et al., 2015).

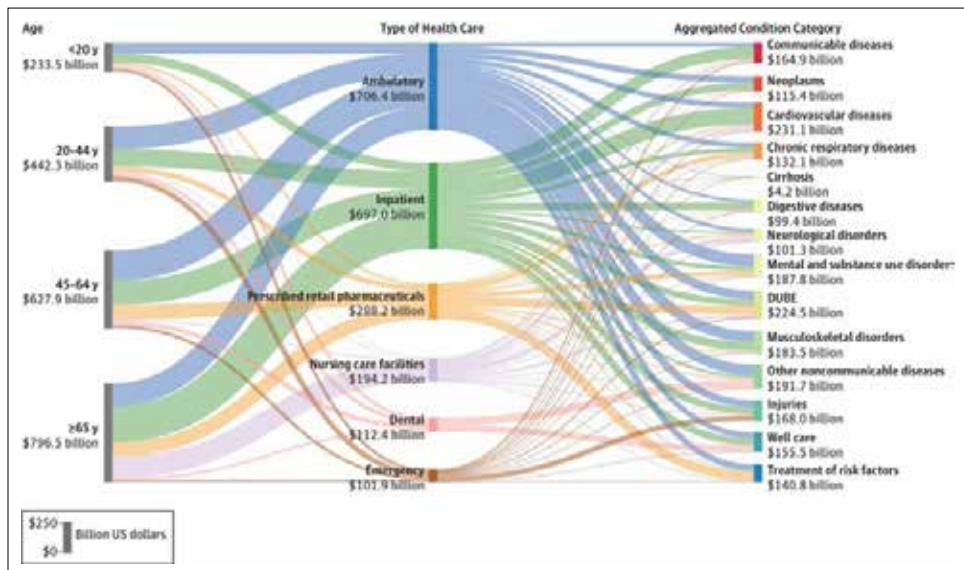
In this paper, we consider the consequences of these troublesome trends and simulate the potential benefits of strategies to alleviate chronic disease burden. We show that our fragmented system spends large amounts of money in a disease-centric model. Mental illness in particular is expensive, but in some cases neglected. Through a series of simulations, we show the potential health benefits of moving to a prevention-based strategy, and we conclude with some thoughts about how we might reward prevention better relative to the dominant fee-for-service model that reimburses for services delivered, and only when a patient is sick.

Fragmentation in Chronic Disease Care

The US spends more than \$2 trillion annually on personal health care spending. This care is delivered in many different settings and for many different conditions, as shown in Figure 1 (reproduced from Dieleman, et al., 2016). Cardiovascular disease and endocrine disorders each account for about \$230 billion of health care spending annually. Musculoskeletal disease and mental illness come next – accounting for around \$180 billion each, slightly more than communicable diseases and injuries. Cancer accounts for \$115 billion, a low number relative to the attention often devoted to its costs. Spending is also concentrated heavily (approximately two-thirds) among adults age 45 and older, with 40% going to seniors 65 and older. Older populations tend to use more inpatient services and younger populations more ambulatory services – an issue we will examine in more detail later.

The costs of treating chronic disease are likely exacerbated by the fragmented US health care system. Ranked last of 11 industrialized nations on measures of health system quality, efficiency, access to care, equity, and healthy lives (Davis, et al., 2014), the United States struggles to deliver the innovative care it works so hard to develop. Lack of coordination in diagnosis (Stange, 2009) and delivery (Enthoven, 2009) practices are both to blame, creating higher costs, wasteful practices (Frandsen, et al., 2015), and, possibly, increased medical errors (Makary and Daniel, 2016). For chronic conditions that involve specialists or are associated with co-morbidities, one common complaint is that multiple care providers do not communicate effectively. For instance, kidney failure patients undergoing dialysis may receive their primary care from a nephrologist, rather than a primary care provider, leading to lower rates of preventive care (V. Wang, et al., 2017).

Figure 1. Personal Health Care Spending in the United States by Age, Condition, and Type of Service



Notes: This exhibit reproduces Figure 1 from Dieleman, et al., 2016. DUBE indicates diabetes, urogenital, blood, and endocrine diseases. Reported in 2015 US dollars. Each of the three columns sums to the \$2.1 trillion of 2013 spending disaggregated in this study. The length of each bar reflects the relative share of the \$2.1 trillion attributed to that age group, condition category, or type of care. Communicable diseases included nutrition and maternal disorders. See source for more detail on the conditions.

That said, the cost issues that arise from this kind of poor care delivery may not be as straightforward to solve. For instance, pushing physicians away from low-value services is a highly effective intervention that does not require any additional coordination of care or communication by providers (McWilliams, 2016). While the United States is very generous at protecting intellectual property like pharmaceuticals and devices (D. Goldman and Lakdawalla, 2012), it pursues a cost-based model for diagnostics (D. Goldman, et al., 2013), and simple strategies to prevent disease in the first place may not be rewarded at all (Agus, et al., 2016).

Prescription drugs account for just under \$300 billion in spending, far less than inpatient and ambulatory services, but still a substantial amount. Not shown in Figure 1 is how spending for drugs has changed over time. As drugs for a range of conditions have improved, we have seen a broad shift from prescription drugs administered in the hospital to higher rates of at-home prescription use. The

types of drugs we use (Figure 2) show the burden of chronic diseases, such as hypertension, as well as more generalized conditions, such as mental health and pain, which together accounted for more than 300 million prescriptions in 2016.

Figure 2. Top US Therapeutic Classes, by Prescriptions (Millions, 2016)

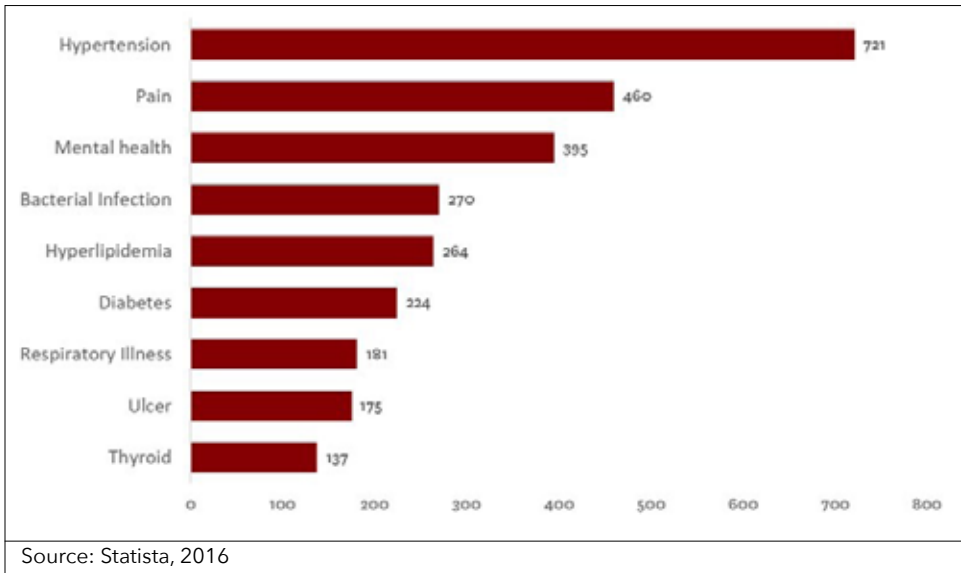


Figure 3, computed using the Medical Expenditure Panel Study (MEPS), shows how the intensity of drug spending has changed over time through the adult lifecycle. Drug spending (as a share of total spending) peaks around age 60, and rose by several percentage points over the last 14 years. Conversely, in-patient spending (Figure 4) has fallen as a share of total spending, and shows a strong age-incidence relationship, as one would expect.

Costs increase substantially as chronic conditions cluster. On average, patients with five or more chronic conditions are 14 times more costly to the overall system than patients with no chronic conditions (Buttorff, et al., 2017). Patients tend to accumulate chronic conditions as they age, implying that Medicare takes on more of the cost as chronic conditions build up, while younger patients with fewer chronic conditions are more likely covered by private insurance (Buttorff, et al., 2017).

The burden of increasing chronic disease is also unevenly distributed across racial and ethnic groups. By 2030, 40% of the Medicare population is expected to be living with three or more chronic diseases (Gaudette, et al., 2015) – up

14 percentage points from 2010. This figure is even greater for non-Hispanic black Medicare beneficiaries, 48% of whom are projected to have three or more chronic diseases by 2030 (Gaudette, et al., 2015). Recent progress in cancer sur-

Figure 3. Prescription Drugs as a Share of Total Health Care Spending by Age, 1999-2001 & 2013-2015.

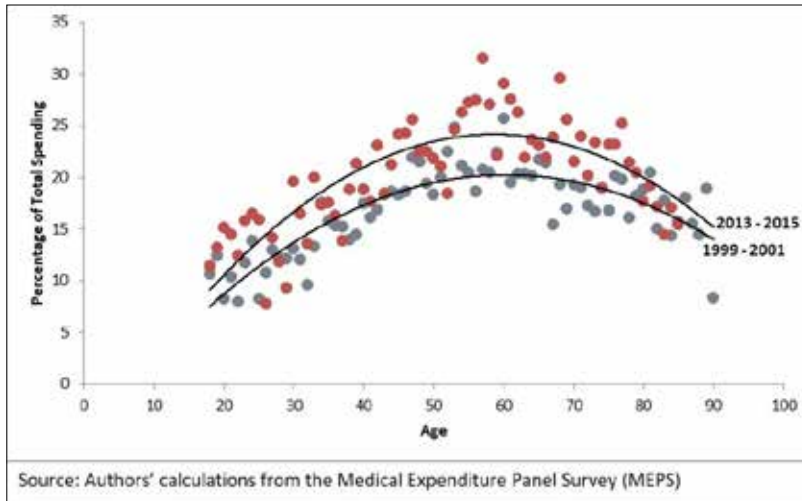
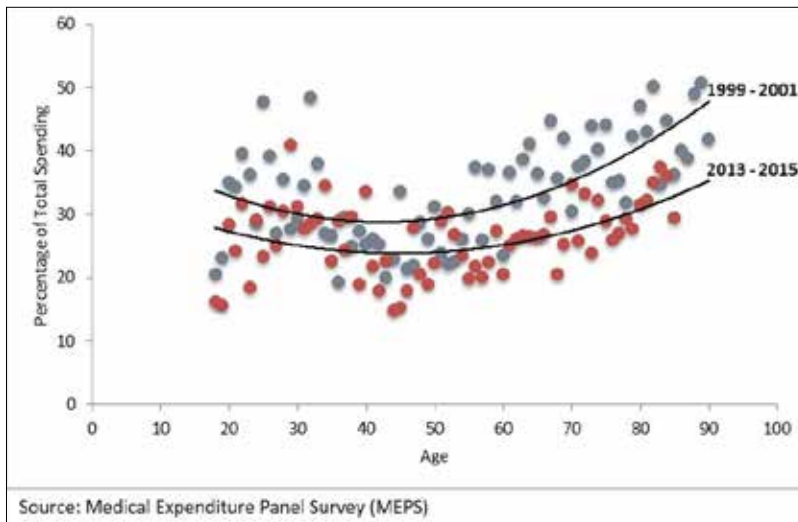


Figure 4. Inpatient Spending as a Share of Total Health Care Spending by Age, 1999-2001 & 2013-2015



vival (Lakdawalla, et al., 2010), coupled with successful efforts to combat cardiovascular disease, Alzheimer's, and other age-related conditions, will exacerbate this trend (D.P. Goldman, et al., 2016). Congestive heart failure is increasing in prevalence and puts an additional strain on elderly African-American women (Van Nuys, et al., 2018). Utilization trends point to racial disparities as well. Since 1998, there has been a jump in hospitalizations from chronic ambulatory care sensitive conditions, meaning conditions that should be successfully managed outside the hospital. There is a growing rate of hospitalizations due to complications from diabetes, chronic obstructive pulmonary disease, or asthma, among patients of color, with over 430,000 excess hospitalizations among non-Hispanic Blacks as compared to non-Hispanic Whites (Doshi, et al., 2017).

Burden of Mental Illness

Estimates suggest that as many as one in four Americans suffers from mental illness, and prevalence has been rising, particularly among adolescents and young adults (Kessler, Berglund, et al., 2005); (Kessler, et al., 2004); (Kessler, Chiu, et al., 2005); (National Academies, 2015). This has had a dramatic effect on health care delivery, including a more than 60% increase in primary care visits with a mental health complaint in approximately a decade (Olfson, et al., 2015); (Olfson, et al., 2014). Causation also runs both ways. The pain and discomfort of chronic conditions can lead to depression and substance abuse, raising costs and worsening patient outcomes. Mental health disorders can also lead to worse health behaviors, increasing the incidence and severity of chronic physical problems.

While it has been well documented that minorities in the US tend to have worse physical health, evidence suggests that minorities may actually be less likely on average to have mental health disorders (McGuire and Miranda, 2008). However, there are important disparities with regard to mental health. For example, African Americans appear to have higher rates of schizophrenia than whites (Neighbors, et al., 2003). Also, some suggest that language and cultural differences affect symptom expression in such a way that causes mental disorders to be under-diagnosed in minority populations compared to whites (Alarcón, et al., 2002); (Westermeyer and Janca, 1997).

What is clearer is that there are disparities in access to care along racial and socioeconomic status lines. Past work has shown that minorities and lower income individuals are less likely to receive mental health care services (Cunningham, et al., 2006); (US Surgeon General, 2001); (McGuire, et al., 2006); (P.S. Wang, et al., 2000). Moreover, when receiving care, minorities tend to receive lower quality care and are more likely to discontinue treatment (Sue, et al., 1994); (Young, et

al., 2001). There is little evidence that the problem is getting better, as recent research suggests that, while use of mental health care has increased since the passage of the *Patient Protection and Affordable Care Act* (ACA, 2010), there was no impact on disparities (Creedon and Cook, 2016).

The nature of mental illness is such that patients often have a hard time finding or keeping work and are highly reliant on public programs for care, particularly Medicaid. Medicaid is the single largest payer in the US for behavioral health services (Levit, et al., 2008). However, relatively low reimbursement rates and provider shortages in mental health mean that these patients have poor access to primary and specialist care, which leads to



worse outcomes and causes patients to be over-reliant on the emergency department for treatment (Cunningham, et al., 2006). There are also high rates of physical co-morbidity for patients with mental health disorders (Dixon, et al., 1999); (Jones, et al., 2004); (Katz, 1996); (Scott, et al., 2009), which can be exacerbated by treatment (e.g., use of atypical antipsychotics is associated with metabolic syndrome, potentially increasing the risk of cardiovascular disease (De Hert, et al., 2008); (De Hert, et al., 2006); (Yumru, et al., 2007). This enhances the need for coordination between providers (Phelan, et al., 2001). While the estimated effects of care coordination have, in general, been mixed (Peikes, et al., 2009), there is some evidence that care coordination can lower hospitalization and health care spending for patients with mental illness (Unützer, et al., 2008).

Victims of Our Past Success

The biomedical and public health communities often focus on battling one disease at a time. This strategy has carried us to important, but costly, innovation (D.P. Goldman, et al., 2005); (Shekelle, et al., 2005). Cancer is perhaps the most salient example (Experts in Chronic Myeloid Leukemia, 2013). It is the second leading cause of death and accounts for approximately one-fourth of all deaths in a year. Yet, after years of trying, we have made progress in treating the disease. Today, cancer patients live longer and healthier lives than those in prior decades. Survival rates for all cancers increased by almost four years from 1988 to 2000, creating 23 million additional life-years and generating \$1.9 trillion in additional value to society, once the health gains are tallied (D.P. Goldman and Philipson, 2014); (Lakdawalla, et al., 2010); (Stevens, et al., 2015); (Sun, et al.,

2010). And the innovators have been handsomely rewarded, with per capita spending on cancer care rising substantially as well. Meanwhile, public health efforts to prevent the disease in the first place, primarily through tobacco control, have saved many lives, but without the hundreds of billions of dollars in spending for treatment. A similar story exists in cardiovascular disease, where we have made progress in both primary and secondary prevention through a combination of public health and medical investments (Ford, et al., 2007).



The result is that older Americans are now far less likely to succumb to just one disease, instead acquiring multiple chronic conditions that contribute to a lengthy period of disability and health care expense. This trend undermines or reduces gains in quality-adjusted life years as many Americans live in relatively poor health at older ages (Bhattacharya, et al., 2004); (Crimmins and Beltran-Sanchez, 2011); (Hulsegge, et al., 2013); (Lakdawalla, et al., 2004); (Lakdawalla, et al., 2010). As people age, they are now much less likely

to fall victim to a single isolated disease than was previously the case. Instead, competing causes of death more directly associated with biological aging (e.g., heart disease, cancer, stroke, Alzheimer's, etc.) cluster within individuals as they reach older ages. These conditions elevate mortality risk, as well as create the frailty and disabilities that can accompany old age.

Fortunately, new research is emerging that has the potential to extend life while reducing the prevalence of comorbidities over the entire lifetime (Kirkland, 2013); (Tchkonina, et al., 2013). Scientists have been asking whether we can decelerate the process by which the cluster of conditions described above arises, making people healthier at older ages and even lowering spending on health care (Butler, et al., 2008); (Fries, 1980); (Fries, et al., 1993); (Martin, et al., 2007); (Miller, 2002); (Sierra, et al., 2009); (Tchkonina, et al., 2013). Simply put, can we age more slowly – thereby delaying the onset and progression of all fatal and disabling diseases simultaneously?

At the practical level, delayed aging means having the body and mind of someone who is years younger than the majority of today's population at one's chronological age and spending a larger proportion of one's life in good health, free from frailty and disability (Butler, et al., 2008); (Fries, 1980); (Vergara, et al., 2004).

Experimental studies involving animal models have already succeeded in accomplishing this in the laboratory (Miller, 2002). By manipulating genes, altering reproduction, reducing caloric intake, modulating the levels of hormones that affect growth and maturation, and altering insulin-signaling pathways, it has been possible to extend the lifespan, and the healthy lifespan, of invertebrates and mammals (Kirkland, 2013); (Sebastiani and Perls, 2012); (Tatar, et al., 2003). There is an ongoing effort to find clinical interventions to delay aging. Some scientists contend that such interventions are sufficiently close to fruition that people alive today will benefit from them (Butler, et al., 2008); (Kirkland, 2013); (Martin, et al., 2007); (Miller, 2002); (Sierra, et al., 2009); (Tchkonina, et al., 2013).

Clearly, prevention shows value to society, even if initiated at older ages. Next, we quantify what the benefits are likely to be for some salient examples.

Potential Benefits of Prevention

To demonstrate the potential societal benefits of a new strategy focused on prevention, we consider three detailed scenarios where investment might yield social dividends: cardiovascular disease, serious mental illness, and aging.

We used the Future Elderly Model (FEM) and Future Adult Model (FAM), two established economic-demographic microsimulations, to examine the impact of possible interventions for each scenario. FEM and FAM are well-suited to this purpose, having been used to assess the financial risk from new medical technologies for Medicare (D.P. Goldman, et al., 2005), the costs of obesity in older Americans (Lakdawalla, et al., 2005), trends in disability (Chernew, et al., 2005), the future costs of cancer (Bhattacharya, et al., 2005), and the health and economic value of preventing disease for Americans age 25 and older (Agus, et al., 2016). Support for these models came from the National Institute on Aging, the Department of Labor, the MacArthur Foundation, and the Centers for Medicare & Medicaid Services.

First, we modeled better prevention of heart disease at older age. Cardiovascular disease, including heart attack and stroke, is the leading cause of death in the United States and a significant driver of health care spending (Jemal, et al., 2005); (CDC, 2015). The usefulness of aspirin to prevent cardiovascular disease is well-recognized. Since the early 2000s, the US Preventive Services Task Force and the American Heart Association have recommended aspirin for primary and secondary prevention of cardiovascular diseases (Bibbins-Domingo, 2016); (USPSTF, 2002, 2009); (Smith, et al., 2006); (Smith, et al., 2001); (Smith, et al., 2011). Evidence is also emerging that daily aspirin use can prevent some cancers (Bibbins-Domingo, 2016); (Cuzick, et al., 2014); (Dube, et al., 2007).

Despite these health benefits, aspirin use remains troublingly low. The US Preventive Services Task Force recommends initiating low-dose aspirin use for the primary prevention of cardiovascular disease (CVD) and colorectal cancer in adults aged 50 to 59 years who have a 10% or greater 10-year CVD risk, are not at increased risk for bleeding, have a life expectancy of at least 10 years, and are willing to take low-dose aspirin daily for at least 10 years. Yet data suggest that less than half the eligible population do so (Agus, et al., 2016).

In prior work, we used the FEM to model the potential benefits of broader use of aspirin among those for whom it is recommended. We find that guideline adherence could substantially reduce mortality in America, adding more than one-quarter of a year of life expectancy (Agus, et al., 2016). Overall, we estimate that 900,000 more Americans would be alive if we had perfect adherence to the current guidelines. Although longer life spans mean an increase in lifetime medical costs, observing the guidelines would yield positive and significant net value and be highly cost-effective (Agus, et al., 2016).

Second, we modeled a prevention strategy to eliminate serious mental illness in young adults. We used the FAM to compare lifetime outcomes for individuals with and without a diagnosis of serious mental illness by age 25. Here we define serious mental illness as a self-reported diagnosis of psychosis, bipolar disorder or major depression, and we simulate the following outcomes over the course of a person's life after age 25: life expectancy, quality adjusted life years (QALYs), medical spending, lifetime earnings, and total income from Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI).

The results, reported in Table 1, show the significant lifetime burden caused by serious mental illness. Someone diagnosed with serious mental illness has more than 11 fewer years of life expectancy and loses more than 12 QALYs (a 26% reduction) compared to someone without. Lifetime medical spending is about 25% higher, while lifetime earnings fall by nearly half and disability income increases dramatically.

These findings demonstrate several important features of both the opportunities and challenges of early intervention and prevention. First, the potential gains to identifying someone with mental illness early and treating them appropriately are significant. Clinical trial results have shown that intensive, patient-centered interventions during early stages of first episode psychosis can lead to significant improvements in health and other outcomes (Kane, et al., 2016).

For example, early intervention via illness and medication management, family psychoeducation, and education/employment support in the "Recovery After an

TABLE 1: SIMULATED LIFETIME OUTCOMES WITH AND WITHOUT SERIOUS MENTAL ILLNESS BY AGE 25

	No Serious Mental Illness	Serious Mental Illness Diagnosed by Age 25	Difference (%)
Life Expectancy, Years from Age 25	56.1	44.8	-11.3 (-20%)
Quality Adjusted Life Years, Years from Age 25	46.2	34.0	-12.2 (-26%)
Lifetime Medical Spending, Thousands of 2016 \$s	653.8	814.5	160.7 (+25%)
Lifetime Earnings, Thousands of 2016 \$s	1011.7	525.5	-486.2 (-48%)
Lifetime SSDI Income, Thousands of 2016 \$s	7.1	51.8	44.7 (+630%)
Lifetime SSI Income, Thousands of 2016 \$s	3.3	23.5	20.2 (+612%)

Source: Authors' calculations based on microsimulation results from the Future Americans Model

Initial Schizophrenia Episode - Early Treatment Program" (RAISE-ETP) was able to improve quality of life and reduce depression symptoms, with larger effects in patients with shorter duration of untreated psychosis (Kane, et al., 2016). From Table 1, we can see that the potential economic effects would be significant. However, the findings also point out that the benefits would be diffuse, in the sense that they would accrue over an extended period of time to many different agents, including the patients themselves, health care payers, and society through lower demand for public support. This makes it challenging to demonstrate the return on investment to a significant and costly up-front intervention strategy.

Third, we examined the economic benefits and costs of delayed aging in an article published in *Health Affairs* (D.P. Goldman, et al., 2013). We primarily looked at the costs of major entitlement programs, specifically federal and state spending for Medicare and Medicaid and federal income support through Old-Age, Survivors, and Disability Insurance and Supplemental Security Income. Economic outputs were aggregated into fiscally relevant variables using benefit rules for particular programs. Annual costs are given in constant 2010 dollars. All cumulative costs are discounted using a 3% annual discount rate (Gold, et al., 1996).

Using the FEM, we developed several scenarios and compared the health and medical spending they would involve. In the status quo, or baseline scenario, we used the mortality forecasts for all-cause mortality in the intermediate projec-

tions of the Social Security Administration (Board of Trustees of Federal Old-Age and Survivors Insurance and Federal Disability Insurance Trust Funds, 2011). We did not change the incidence of disease. Heuristically, in this scenario mortality improvements can be seen as the result of improved treatments for people with disease.

We then compared the status quo with a delayed aging scenario. We assumed that improvements in mortality and health started earlier in life than they did in the disease-specific scenarios. We assumed that the slope of the intrinsic mortality curve, that is, mortality from factors such as age, as opposed to exposure to external risks such as trauma or smoking, observed in 2000 for both men and women ages 15-50 would decline by 20% by 2050. These hypothesized changes are consistent with research on the biology of aging, which suggests that the health benefits of delayed aging would begin at puberty, the time when mortality begins rising exponentially (de Magalhaes, et al., 2005).

The results were dramatic. Life expectancy at age 50 in 2030 was 35.8 years in the status quo, similar to Social Security Administration projections (Board of Trustees of Federal Old-Age and Survivors Insurance and Federal Disability Insurance Trust Funds, 2011). In the delayed aging scenario, however, it increased to 38 years, an improvement of 2.2 years. Of course, it matters whether these survivors would be healthy or disabled. We found that the delayed aging scenario yielded a smaller share of seniors disabled every year, resulting in lower per capita Medicare spending.

However, overall costs were higher by hundreds of billions of dollars because more seniors were alive to accrue benefits from Social Security, Medicare, and Medicaid. This demonstrates our current dilemma with demographic progress. Delayed aging added \$420 billion to entitlement spending in 2060. As a result, we also modeled a variant of the delayed aging scenario that included an adjustment to the eligibility age for Medicare and the normal retirement age for Social Security. Social Security provides a strong precedent for such a policy fix. The Social Security Amendments of 1983 raised the normal retirement age from 65 to 66, with ongoing gradual increases such that the normal retirement age will rise to 67 for people born in 1960 and later (*Social Security Amendments of 1983*, 1983).

Our “eligibility fix” consisted of a gradual increase in the eligibility age for Medicare from 65 to 68, and for Social Security from 67 to 68, extending the *Social Security Amendments of 1983*, which mandated gradual increases in the retirement age over a 22-year period starting in 2000, for about ten years. This

eligibility fix brought net fiscal burdens back to the status quo. Overall, the findings indicate that delayed aging would generate more than \$7 trillion in health benefits, but with substantial challenges to our current entitlement programs. However, reasonable policy fixes make them manageable.

Discussion

The previous simulations point to the enormous untapped potential of prevention. Some critics might argue we do not know how to achieve these gains, but this misses the point. As a society, we routinely underinvest in finding ways to prevent disease, so it is no surprise that we have not discovered a way to do it. Just as our reimbursement model discourages innovation in preventive technology and treatment, the playing field is tilted away from early interventions that can have long-term benefit. These interventions range from straightforward activities like promoting exercise or proper nutrition, to more substantial ones, such as early diagnosis and treatment of first episode psychosis. We reimburse for hospitalizations, rather than keeping patients out of the hospital. Aspirin is instructive. In some ways, the problem is that it is too cheap. Only 40% of Americans are taking aspirin when they should, and providers have little incentive to push that number up, despite the obvious health benefits and health care savings. Until we figure out how to reward providers and manufacturers for long-term outcomes, use will remain frustratingly low.

This short-term thinking is endemic to our approach to financing. On the system side, this reflects the short-term nature of insurance contracts. We choose our plans annually, and so we tend to focus on annual spending and use. On the patient side, these contracts reinforce a fundamental problem with health behavior; namely, that we have a hard time internalizing investments that will pay (health) dividends much longer down the road. Thus, we underinvest in disease prevention and cures. Preventing diabetes (or developing a cure) would be worth trillions of dollars to Americans, yet there is a paucity of research into how to do so. The experience with a cure for hepatitis C exacerbated the problem, because, when viewed through a long-term lens, these drugs were well worth the money, but people focused on the cost per pill, which is hardly the right metric.



One issue arises: If prevention is so valuable, why isn't it in the individual's interest to pursue it? This is not entirely clear. We are starting to learn more through cognitive science. For example, different regions of the brain activate when we make long-term versus short-term decisions. Short-term decisions involve regions associated with emotions; whereas we tend to activate the abstract reasoning part when making long-term decisions. However, while we are starting to understand it, we can't do much about it.

There is also a disconnect between the ultimate payers (beneficiaries) and the intermediaries who are doing our negotiating. At the end of the day, it is the employers and the government who decide what is going to be covered, not an insurer, and, as a society, we can decide that we want to start reimbursing for long-term health outcomes.

What can be done? We can start by finding ways to lengthen insurance contracts. There is nothing magical about annual contracts; perhaps we could go to five years to start. Even without longer contracts, we could also install a system that would reward plans for reimbursing care that was in the patient's long-term interest, but not in the plan's short-term interest. This would involve side payments between plans for recommended care. For example, when a patient with treated hepatitis C moves between plans, the receiving plan would pay the original plan for the treatment. Conversely, if the plan knew about the hepatitis C and did not treat it, they would need to compensate the new plan.

Extending the case of hepatitis C, for example, the scenario would have involved a series of payments as long as the patient remained virus-free. This annuitizes the high upfront cost, and makes it dependent on performance. There are other examples from the newer PCSK9i cholesterol-lowering drugs. These have been shown to reduce "bad" cholesterol levels for people for whom statins don't work. While they reduce cholesterol, we do not yet know for sure whether they save lives by reducing cardiovascular events. One could pay based both on cholesterol improvement, which is easier to measure, and the long-term outcomes (hospitalization for a cardiovascular event), to ensure that payment is tied to value.

We are seeing the private sector take steps in these directions on both the insurer and the manufacturer side. There are two hurdles, however, as relates to prescription drugs. The first is regulatory: It is not clear how such contracts affect Medicaid "best-price" rules (which require Medicaid to get the best price offered to any buyer), and it is not clear how the Food and Drug Administration (FDA) would react if the contracts were to consider outcomes, such as hospitalizations or ER visits, that are not on the label. The second is the ability of the insurers to

track outcomes over time. In an integrated delivery system such as Kaiser Permanente, where patients stay for many years, this is straightforward. It is not so clear how to do it with a pharmacy benefits manager (PBM) such as Express Scripts, which only sees the pharmacy data and not the lab or hospitalization data.

The 30-day readmission penalties in the *Patient Protection and Affordable Care Act* (ACA, 2010) for heart attacks, heart failure, and pneumonia had much larger effects on behavior than people expected. These penalties only put about 1% of hospital reimbursement at risk. Hospitals are starting to examine their discharge strategies and coordinating care in the community to make sure the patient has adequate follow-up. Imagine what would happen if 25% were at-risk and tied to one-year outcomes. Even better, suppose hospitals were paid to keep certain high-risk patients out of the hospital in the first place. The results could be profound.

While progress in reducing the burden of chronic diseases will undoubtedly include scientific innovation, the key to reaping the fruits of that labor will be our ability as a system to move to a model that rewards positive health outcomes, not health care resource use.

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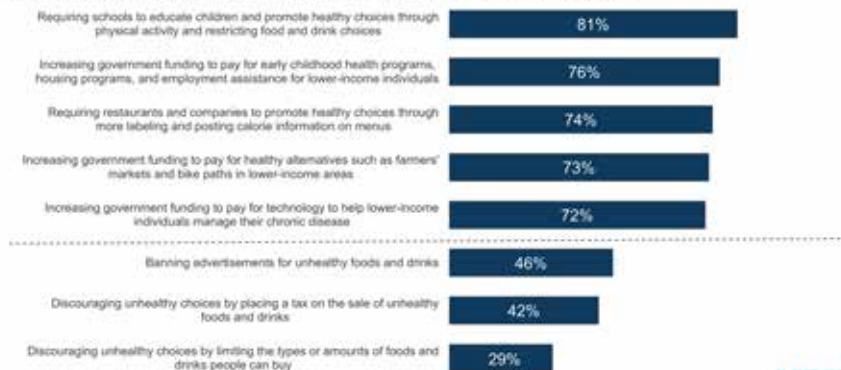
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Majorities of Americans Favor Initiatives To Promote Healthy Behaviors, But Fewer Favor Bans or Taxes

Percent who say they favor the following approaches aimed at preventing or managing chronic diseases:

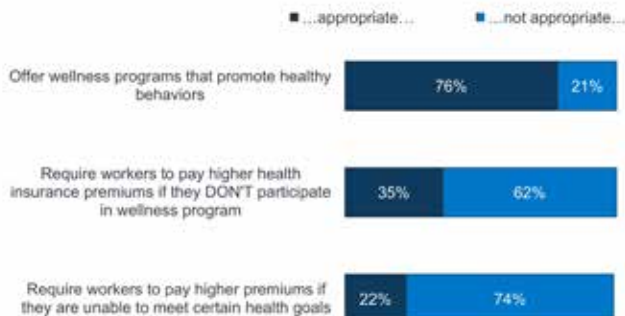


NOTE: Items asked of separate half samples.
SOURCE: KFF Health Tracking Poll (conducted April 20-30, 2014)



Most Americans Think It's OK For Employers To Offer Wellness Programs, But Not To Tie Premiums To Participation Or Health Outcomes

Percent who say each of the following is...for employers to do:



NOTE: Don't know/Refused answers not shown.
SOURCE: KFF Health Tracking Poll (conducted June 12-18, 2014)



“Communities across the globe are implementing an astonishing array of experiments designed to grab the tail of chronic disease while building an evidence base of what works to reduce its prevalence.”

– VINCENT LAFRONZA, ED.D., M.S., and LISA TOBE, M.P.H., M.F.A.

Models to Prevent Chronic Disease and Create Health in Communities

Vincent Lafronza, Ed.D., M.S., and Lisa Tobe, M.P.H., M.F.A.

Public health is “what we as a society do collectively to assure the conditions in which [all] people can be healthy.” (Institute of Medicine, 1988)

After a brief introduction to the chronic disease burden in the US, this paper highlights promising or evidence-based approaches underway to reduce disease burden and improve public health outcomes. We seek to stimulate new ideas for solutions to prevent chronic disease nationally.

Overview

Chronic disease accounts for approximately 66.7% of all deaths in the US (Table 1) (Heron, 2017). This means that as Americans we die prematurely from coronary disease, cancer, chronic lower respiratory disease, diabetes, and mental health conditions (that lead to overdose and suicide); deaths that are largely preventable. Over 60% of US residents live with at least one chronic condition and 42% live with two or more (Buttorff, 2017). By 2015, almost 200 million (191 million) people in the United States had a chronic disease, with 75 million having two or more (National Center for Health Statistics, 2016). By 2030, epidemiologists project the number of Americans with one or more chronic diseases will increase by as much as 37%, which equates to 46 million more people with diseases that could have been prevented. In addition, by 2030, experts predict over ten million people will be living with Alzheimer’s disease, more than 215 million will be obese, 53 million will have diabetes, and the prevalence of arthritis, asthma, and cardiovascular disease will all rise substantially (Alternative Futures, 2014).

Chronic disease is not limited to physical illness. Mental health disorders (bipolar/post-traumatic stress/obsessive compulsive disorders or depression) are medical conditions that significantly impact an individual’s ability to think, function, interact with others, and perform daily tasks (CDC, 2012). In a given year, approximately one in five individuals (more than 40 million Americans) will ex-

TABLE 1: US LEADING CAUSES OF DEATH 2000 - 2015

	Prevention Component	Chronic Condition	2000 Rate	2015 Rate	Change
Heart Disease	√	√	257.6	168.5	-89.1
Cancer	√	√	199.6	158.5	-41.1
Chronic lower respiratory diseases	√	√	44.2	41.6	-2.6
Unintentional Injuries	√	√	34.9	43.2	8.3
Stroke	√	√	60.9	37.6	-23.3
Alzheimer's Disease		√	18.1	29.4	11.3
Diabetes	√	√	25	21.3	-3.7
Influenza & Pneumonia	√	√	23.7	15.2	-8.5
Kidney Disease	√	√	13.5	13.2	-0.3
Suicide	√		10.4	13.3	2.9

Source: National Center for Health Statistics, 2017

hibit a mental health disorder. (National Alliance on Mental Illness, 2016). Over the past three years, the rate of severe depression in youth increased substantially, from 5.9% in 2012 to 8.2% in 2015. More than 1.7 million youth exhibiting depressive episodes failed to receive treatment (Mental Health America, 2018). Those with chronic diseases also have a higher likelihood of depression (Chapman, 2005).

Communities across the globe are implementing an astonishing array of experiments designed to grab the tail of chronic disease while building an evidence base of what works to reduce its prevalence. From place-based strategies to policy reforms, some are making headway. In the US, our national data show uneven progress. In some areas health outcomes are worsening (e.g., mental health disorders). While health experts used to think that behavior, genetics and access to quality health care services contributed the most to these outcomes, we have recently begun to accept that much larger structural issues create them.

Contemporary US public health practice evolved over the past 150 years from a system entirely designed to protect against the spread of infectious disease. Under the US Constitution, states possess health powers (e.g., isolation; community vaccination; licensure of medical professionals; responding to public health emergencies). These actions are bounded by federal authority to tax, spend,

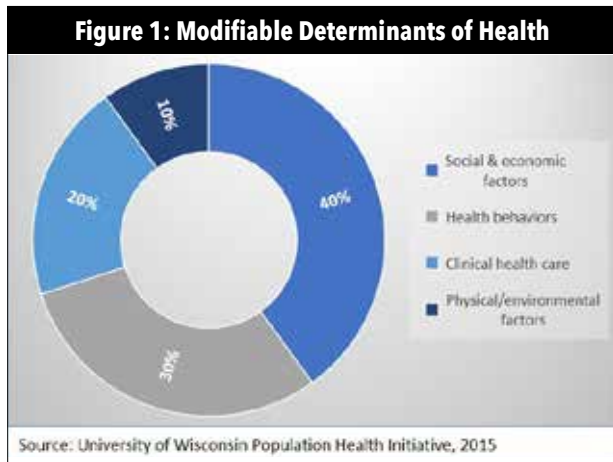
and regulate public interstate commerce and individual rights to privacy, liberty, property, and other legally protected freedoms (Gakh, 2015). This complicated balancing of community and individual interests results in uneven interventions throughout the 50 states and territories.

Socially Constructed Health

Historically, public health practice, the medical model, and society in general tended to blame genetics, limited health care access, ignorance, and individual actions for the predominance of chronic disease, particularly among vulnerable populations. Focusing on downstream solutions, such as raising awareness about risk factors, providing access to health care, or advising people to change

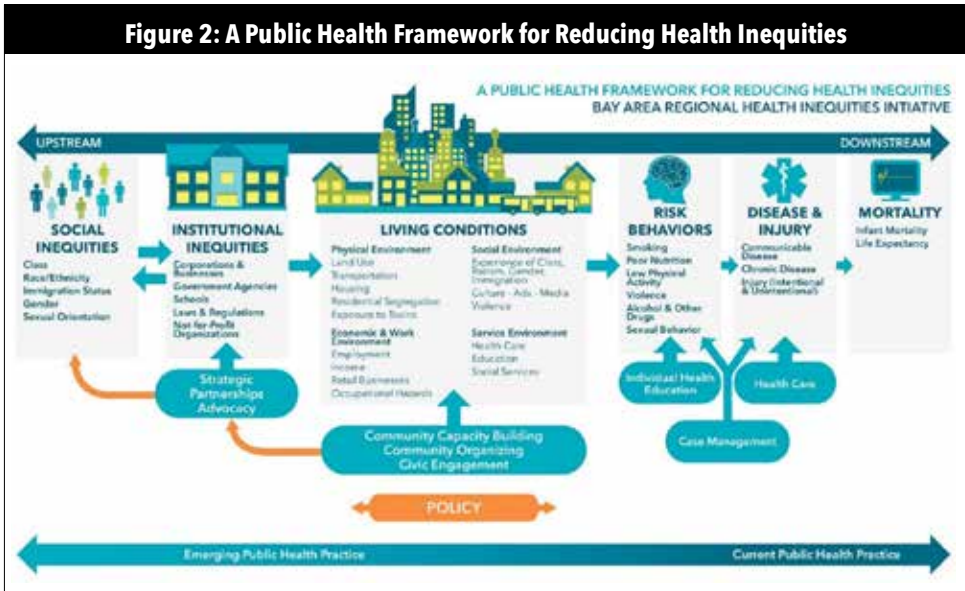
their behavior does little to address the root causes of health inequities. In 2015, University of Wisconsin Population Health Institute researchers estimated the percentage of people's health (including the length and quality of life) affected by factors that can be changed or "modifiable determinants of health" (Figure 1) (Park, et al., 2015). This provided clinicians, researchers, activists, government agencies, community-based organization staff and other practitioners with clarity on where to prioritize their efforts to prevent chronic disease.

Research shows chronic diseases account for a major portion of the life expectancy gap between whites and blacks (Dankwa-Mullan, et al., 2010); (Thomas, et al., 2011); (Freudenberg and Olden, 2010). More than measuring disease prevalence, we must examine the causality of disease burden (Thomas, et al., 2011). While disparities in incidence and outcome reflect a complex host of factors (including socioeconomic status (SES), differences in life styles, diet, smoking rates, and unequal access to care and community support structures), disparity trends seem to hold constant in some capacity even when these known risk factors are accounted for in regression models, indicating that they do not fully explain the differences between groups (Humana Press, 2014); (DeSantis, et al., 2016); (Haiman, et al., 2006).



Racism and Discrimination as Drivers of Chronic Disease

Racism, historical trauma and other forms of discrimination have resulted in elevated yet preventable levels of illness, injury, and death for people of color and impact all Americans. To assist health advocates, the Bay Area Regional Health Inequities Initiative (BARHII, n.d.) created a Public Health Framework for Reducing Health Inequities, which illustrates upstream and downstream factors driving health outcomes. They also describe an emerging public health practice (Figure 2) accounting for living conditions, institutional inequities and social inequities, which calls for public health practitioners to focus on policy through community capacity building, community organizing, civic engagement, advocacy and strategic partnerships (BARHII, n.d.).



Policy Options for Preventing Chronic Disease

Since structural inequities have been incorporated in the systems that govern and directly impact health outcomes, implementing policy changes is one of the most direct methods to disrupt these drivers. In this section, we present the use of regulation, taxation and incentives as policies that could decrease chronic diseases, particularly those related to prevention, healthy eating and active living, and tobacco control. Policy levers can impact large populations. Freudenberg and Olden (2010) argue, "Preventing exposure to automobile exhaust and to-

bacco smoke and using regulatory and policy levers to reduce smoking, alcohol abuse, and consumption of foods high in fat, sugar, and salt could save millions of lives” (p. S27).

In 2001, the Centers for Disease Control and Prevention (CDC) published the Guide to Community Preventive Services: Systematic Reviews and Evidence-Based Recommendations (CDC, 2001), commonly known as the Community Guide. This online resource contains evidence-based findings from efforts that worked to improve health and prevent disease. The Guide, which covers more than 20 topic areas (many of which include chronic disease) also contains cost data and identifies known evidence gaps.

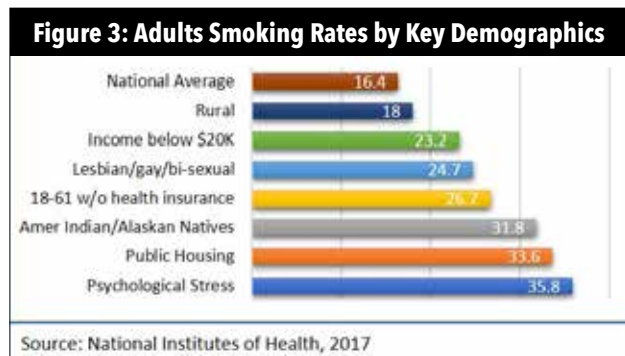
Tobacco Control Models Show Promise

Cigarette smoking, the leading cause of preventable disease and death in the US, accounts for more than 480,000 deaths (one in five) annually. In aggregate, tobacco smoking causes four out of five US lung cancer deaths (women 83.7% and men 80.7%) (Jamal, et al., 2017); (NIH, 2017). Disparities exist among those most impacted (Figure 3) (NIH, 2017).

A plethora of research demonstrates the effectiveness of several policy solutions such as smoking bans, purchase age increase, taxes, and mandated insurance coverage for tobacco cessation (Text Box 1). When integrated into a comprehensive tobacco control program, which includes mass media campaigns, these strategies have decreased tobacco use, related mortality, and health care spending across all SES and racial/ethnic groups (NIH, 2017).

Taxes dampened the demand, supported cessation supports, and funded powerful educational and advertising campaigns that changed social norms around tobacco usage (CDC, 2014). This inspired community and youth-led initiatives focused on decreasing tobacco-related illness.

In a review of 40 studies that use simulation models, Truth Initiative researchers found that taxation, youth prevention, smoke-free policies, mass media cam-



paigns, marketing/advertising restrictions and product regulation could be effective. In particular, they noted that tax hikes of \$.71 to \$4.63 per pack would reduce cigarette consumption by 8% to 46%; a national indoor workplace smoking ban would cause 725,000 current smokers to quit; and raising the minimum age of purchase to 21 would reduce use by 14.6% among 15- to 17-year-olds (Feirman, et al., 2017). In particular, price increases for tobacco products decrease usage among youth and low-income populations, making this an effective policy tool to reduce related disparities from tobacco use.

TEXT BOX 1: OTHER TOBACCO POLICIES

- ✓ Prohibiting smoking and tobacco use in public spaces
- ✓ Establishing minimum pack sizes and prices for tobacco products
- ✓ Prohibiting the sale of tobacco products by certain retailers
- ✓ Reducing the number of tobacco retailers in a community
- ✓ Restricting the location of tobacco retailers

In November 2016, the US Department of Housing and Urban Development (HUD) mandated that all public housing authorities go smoke-free. A press release cited improved in-door air quality, better health for residents and staff, a reduced fire risk, and lower maintenance costs as reasons. HUD estimated it will save public housing agencies up to \$94 million in second-

hand smoke-related health care. This policy has significant promise as it potentially could impact more than seven million individuals served by the US public housing program (Winickoff, et al., 2010).

Researchers have shown that access to clinical and behavioral interventions reduces smoking rates among participants. As part of its mandated health coverage, MassHealth Medicaid provided patients with access to tobacco cessation medications and counseling. Broadly promoting this benefit led to a cascading level of benefits for the patients and state, including a 26% decrease in state smoking prevalence in just two years. Longitudinal studies during the same time period showed “significant annual declines in Massachusetts Medicaid claims for hospitalizations for acute myocardial infarction and acute coronary heart disease” (Land, et al., 2010, p. 1). Some racial/ethnic populations, young adults, individuals with low income and those without insurance are less likely to receive recommendations to quit smoking, or cessation support. This decreases their use of evidence-based treatments (Murray, et al., 2009), which makes these findings particularly relevant to those populations. Clinical practice guidelines recommend health care system changes to prompt, guide, and incentivize tobacco treatments,

and provide evidence-based treatments via the Internet and phone. Additionally, the Task Force on Community Preventive Services endorses increasing the unit price of tobacco products, reducing client out-of-pocket costs for effective cessation therapies, developing multicomponent interventions that include client telephone support, and incorporating provider reminder systems and provider education programs (Community Preventive Services Task Force, n.d.).

Food Security Drives Decreased Chronic Disease Rates – The Role of Taxes and Subsidies

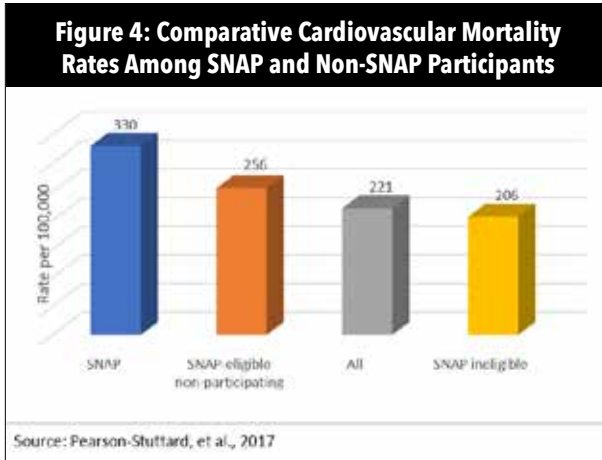
Reducing obesity would clearly reduce chronic disease. Various environments contribute to the epidemic including: social (e.g., family, school, community, workplace, social norms, mass media, food marketing, nutrition education, etc.); physical (e.g., urban design, sidewalks, parks, food outlets, exercise facilities, transportation, etc.); and economic policy (e.g., taxes, subsidies, direct pricing, serving size regulation, nutrition labeling, etc.) (Sturm and An, 2014).

With respect to economic policy incentives, a growing evidence base indicates that “changes in the relative prices of less healthy and healthier foods and beverages can significantly change consumption patterns” (Powell and Chaloupka, 2009, p. 9). A systematic review and meta-analysis of interventions and observational studies showed that subsidizing healthful foods significantly increased consumption, while taxing unhealthy foods and beverages reduced intake (Afshin, et al., 2017).

Research has noted the impact among high risk populations. Several studies demonstrate effectiveness with Supplemental Nutrition Assistance Program (SNAP) participants, an important group on which to focus. Individuals who have high cardiovascular mortality rates disproportionately constitute this population compared to those ineligible for SNAP (330 versus 205.7 respectfully) as demonstrated in Figure 4. By examining the cumulative effectiveness and cost savings related to subsidies on fruits and vegetables and taxes on high fat food, research has shown them to be a cost-effective approach to reduce obesity and associated chronic disease risks (Cobiac, et al., 2010).

Strong evidence shows that lowering prices for fruit and vegetables generally increases their consumption, some of which also demonstrates decreased weight in populations studied. This effect has been stronger among SNAP participants, a pertinent policy finding given that subsidies would likely be targeted towards children, and families with low income, and among those with higher body mass index (BMI) (Powell, et al., 2012). The Healthy Incentive Pilot, sponsored by the

US Department of Agriculture, tested incentives among 7500 SNAP households in a randomized study in a western Massachusetts county. Each family received 30¢ in cash back for every \$1.00 spent on fruits and vegetables. After one year, the study demonstrated that those receiving the incentive consumed one-quarter of a cup more of



fruits and vegetables (F&V) daily and spent \$1.29 more monthly on F&V than the control group who only received traditional benefits (Bartlett, et al., 2014). When Afshin, et al. pooled studies, they found that each 10% decrease in the price of F&V increased consumption by 16% (95% CI: 10% to 23%) (Cawley, 2015).

These policies can also have a strong impact on the market. A 2009 change in the Women, Infants, and Children (WIC) program which encouraged purchases of healthier foods (added more fruits and vegetables to the food packages) led to:

- higher retailer stocking rates of healthy foods;
- decreased juice (24%) and whole milk (50%) purchases; and
- increased purchasing of fresh fruits (29%), vegetables (29%), and whole grains (three-fold increase in 100% whole grain bread; five-fold increase in brown rice)

(Whaley, et al., 2012).

Researchers (Thow, et al., 2018, p. 207) argue that food taxes should be “implemented on a large geographical scale, designed with graduated thresholds for the nutrients of concern and cover a broad range of non-core food items that are energy-dense and nutrient-poor” and that the tax amount should equal “marginal external costs, e.g., those associated with additional medical care and higher job absenteeism, that would otherwise be imposed on society.”

The latest example of these policies in the US is taxing sugar-sweetened beverages (SSB). In a 2017 overview of studies related to SSB taxes, the authors noted

that each 10% increase in price decreased consumption by 6% (95% CI: 4% to 8%) (Afshin, et al., 2017). Although previously implemented successfully in international communities, US cities began using this tax in 2016. In Berkeley, consumption of SSB declined by 21% among consumers with low socioeconomic status over a one-year period from before the tax to after the tax (Falbe, et al., 2016).

Afshin, et al., (2017) used the US IMPACT Food Policy Model to predict the effects of policies related to F&V and excess intake of SSBs. They found that the first year of national taxes on SSBs would:

- cost \$51 million;
- reduce sugar-sweetened beverage consumption by 20% and mean BMI by 0.16;
- avert 101,000 disability-adjusted life-years from 2015 to 2025, while gaining 871,000 quality-adjusted life-years; and
- result in \$23.6 billion in health care cost savings and generate \$12.5 billion in annual revenue.

Researchers note that simulation modeling can inform the design of nuanced fiscal policies, such as combinations of specific food targets, taxes, and subsidies to improve nutrition and health in vulnerable populations. Revenue generated by taxes can be used to support interventions focused on improving diets, increasing activity, and reducing obesity, including subsidies for healthier foods and beverages. They can reinforce efforts to increase public awareness about the products' negative impact on health. In addition, taxes levied against manufacturers may encourage them to reformulate products to reduce fat or sugar content (Afshin, et al., 2017).

Built Environment and Health – Policies that Equalize Risk

Through a complex interplay of social, economic and structural determinants such as environmental quality, access to opportunities, community assets and wealth, and presence of commercial services, neighborhoods strongly impact health outcomes (Text Box 2) (IOM Transportation Research Board, 2005). Moreover, research demonstrates that neighborhoods can affect all-cause mortality, mental health, depression, violence, child and maternal health, and other general health (Arcaya, et al., 2016). "The built environment conceived and executed through public policy and investments can create or block healthy lifestyle choices and, therefore, drives or deters chronic diseases" (Williams, 2013, p. 6).

TEXT BOX 2: RISK AND PROTECTIVE FACTORS RELATED TO RESIDENCY*

Built Environment and Infrastructure: Housing, parks, recreation facilities, utilities.

- Protective factors: Access to affordable, high-quality housing, local parks, opportunities to walk, run, and bicycle. Design that supports physical activity.
- Risk factors: Exposure to lead paint, problems with inadequate sanitation and pest infestation, dangerous types of work, and design that inhibits physical activity.

Environmental Quality: Air, water, land.

- Protective factors: Policies and practices that maintain a clean, healthy environment.
- Risk factors: Presence of and exposure to toxics and pollution in residential and work environments.

Employment, income, wealth, and assets: The quality and quantity of employment opportunities available to residents and the amount of collective wealth and assets in the community.

- Protective factors: Living-wage jobs with health benefits; safe workplaces. Savings, retirement, and homeownership provide economic stability.
- Risk factors: Large numbers of community residents with low-wage jobs with no benefits and unsafe working conditions. Racial and economic segregation and concentrated poverty lead to higher stress and premature mortality.

Geographic Access to Opportunities: Access to roads or transit connecting to resources within the neighborhood as well as the broader region.

- Protective factors: Convenient location and mobility allow access to services, employment, and cultural and recreational resources.
- Risk factors: Isolation from job centers, particularly areas without convenient public transit access. Distance from recreational facilities or safe parks for health-promoting activities such as exercise.

Neighborhood economic conditions: Presence of commercial services, including grocery stores, banks, and restaurants.

- Protective factors: Attracts public and private investment in services and infrastructure.
- Risk factors: Disinvestment leads to job and businesses loss and a decline in property values.

*Adapted from the work of PolicyLink and California Endowment, Why Place & Race Matter (Bell and Lee, 2011)

People who live within a half mile of parks and playgrounds or within a mile of recreation facilities are more likely to exercise than those without similar access (Babey, et al., 2013); (Sallis, et al., 1990). Proximity to diverse destinations (e.g., schools, employment, shopping, parks and places of worship) and safety features (i.e., street crossings, bike lanes, traffic circles and stop lights) increases the use of walking and biking, otherwise known as active transportation (Sallis, 2012). According to a 2012 Institute of Medicine (IOM) report, “Enhancing the physical and built environment for physical activity involves changes in land use policies and practices designed to make entire communities and neighborhoods more amenable to physical activity, whether that activity is transportation related or exercise done purposefully in recreational or discretionary time” (Text Box 3) (IOM, 2012, p. 137).

This can be particularly true in communities of color and populations with low income, where research showed that residents have 46% lower odds of having at least one recreation facility (Sallis, 2012). In a review of built environment and health behaviors, researchers found that African Americans were more likely to participate in physical activity when they felt safe from crime and lived in locations with light traffic and sidewalks (Casagrande, et al., 2009).

TEXT BOX 3: SAMPLE POLICY AND STRUCTURAL INTERVENTIONS

- improved connectivity of transportation arteries
- landscaping and lighting to enhance the aesthetics and perceived safety of the community
- tax incentives for developers to build sidewalks and trails in new developments
- zoning changes to require pedestrian access
- communitywide program to encourage bicycling
- coordinated policies to promote bicycle commuting
- community design planning and zoning that increase the proximity of residential areas to workplaces, schools, and areas for leisure and recreation
- marked street crossing areas or pedestrian bridges over multi-lane highways
- traffic-calming strategies, such as traffic circles, stop lights, and signs or speed bumps
- bicycle lanes and pedestrian bridges

Placemaking, a multi-faceted approach to the planning, design and management of public spaces galvanizes people to collectively reinvent public spaces. “More than just promoting better urban design, placemaking facilitates creative patterns of use, paying particular attention to the physical, cultural, and social identities that define a place and support its ongoing evolution” (Project for Public Spaces, 2018). This emerging approach to community-driven revitalization improves social capital, sense of community, and individual well-being (Semenza, et al., 2007). The Framework for Addressing and Preventing Community Trauma supports this assets-based approach as a way for communities to recover from systemic trauma. “Reclaiming public space to be appealing to residents, reflective of community culture, and a source of pride can contribute to a sense of community worth and be supportive of healing” (Pinderhughes, et al., 2015, p. 5).

Reducing Exposure to Violence – An Emerging Prevention Approach

Researchers have found several adult chronic health conditions, including obesity, heart disease, alcoholism, and drug use are directly related to childhood adversity (Pinderhughes, et al., 2015). This understanding contributed to the development of the “life-course perspective,” insight into the factors that determine the health of an individual from infancy to adulthood. In other words, “What happens in different stages of life is influenced by the events and experiences that precede it and can influence health over the life span” (American Academy of Pediatrics, 2014, p. 2). These effects can be diffused through generations and across entire communities when social structures fail to address traumatic experiences. For example, American Indian/Alaskan Native (AI/AN) populations have increased prevalence and risk factors for depression, suicide, drug and alcohol abuse, and PTSD (National Academies, 2017); (Bassett, et al., 2014).

The Prevention Institute built on this concept to explain how violence and trauma affect neighborhoods and conversely, the residents who live within them. Its Framework for Addressing and Preventing Community Trauma challenges people to think in terms of population health and the determinants of health as they relate to violence (Pinderhughes, et al., 2015). The Framework conceptualizes community as a connection among three environments - equitable opportunity; people; and place from which symptoms and community resiliency evolve (Text Box 4). “A traumatized community is missing the fabric and foundation of resilience for young people, children, and families exposed to interpersonal and structural violence (National Academies, 2016, p. 1). A range of strategies would enhance community resilience and break down the blocks of systematic trauma.

TEXT BOX 4: FRAMEWORK SOLUTIONS BY COMPONENT

- **Equitable Opportunity:** Restorative justice, healing circles, economic empowerment and workforce development, increased community wealth and resources
- **People:** Rebuild social relationships and broken social networks; strengthen social norms that encourage healthy behaviors, community connection and community oriented positive social norms
- **Place:** Create safer public spaces through improvements in the built environment through addressing parks, housing quality and transportation; reclaim and improve public spaces (i.e., place making)

Source: Pinderhughes, et al., 2015

Tax incentives for businesses to foster economic and workforce development; participatory budgeting where residents have direct input in the fiscal future of their community; community-driven land planning processes; low-or no-interest loans to allow constituents to invest in homes or education; liquor license moratoriums in high-risk communities; trauma-informed criminal justice and social service systems; educational pipelines that connect residents to living and high wage jobs; and investments in community revitalization efforts and re-entry programs are some examples of effective strategies that facilitate community empowerment and decrease inequities.

Applying Multisector Strategies to Prevent Chronic Disease

Fifteen years ago, the Institute of Medicine issued recommendations that called for increasing multisector efforts to improve public health outcomes (IOM, 2003). Since that time, a plethora of collaborative health improvement efforts emerged in nearly every community throughout the US. Public and private sector grants increasingly required multisector interventions. Research suggests that multisector strategies can successfully solve complex public health issues. In a comprehensive evidence review of dozens of partnerships, Mays and Scutchfield found affirming evidence of multiorganizational effectiveness in improving health (Mays and Scutchfield, 2010). Specifically, their review of 34 public health partnerships showed that ten groups achieved improved health outcomes on specific targets (e.g., infant mortality, lead poisoning, adolescent pregnancy, and motor vehicle injuries); another 32 partnerships demonstrated partnership success as measured by improvements in tobacco and alcohol use rates, and increases in physical activity and safe sex practices. Mays and Scutchfield (2010)

also found that 22 partnerships demonstrated beneficial changes to policies, programs, or environments via smoking bans, changes to school lunch menus, and creation of community exercise trails.



These multisector activities recommended by the Institute of Medicine (now known as the National Academy of Medicine) and other scientific and professional advisory groups included: conducting assessments of health status and needs in the local area; developing shared priorities and plans for health improvement; educating community residents and leaders about health priorities; investing resources in shared health

priorities; and, evaluating the investment results. By analyzing data spanning 16 years, the review demonstrated that deaths from preventable causes such as cardiovascular disease, diabetes, influenza and infant mortality declined significantly among communities that implemented a broad spectrum of population health activities through dense networks of collaborating organizations (Mays and Scutchfield, 2010).

The communities with the strongest networks supporting population health activities showed 20% lower preventable deaths compared to communities with less comprehensive networks. These differences in mortality persisted after controlling for a wide range of demographic, socioeconomic, and health resource characteristics in the communities, including using methods to control for unmeasured community differences. While this evidence is welcomed, we also know that not all partnerships achieve the outcomes they seek. As Mays and Scutchfield (2010, p.5) note “The types of partnerships likely to have the most direct effects on population health are among the most difficult, and therefore least prevalent, forms of collaboration.”

In the following section, we lift up eight complex examples of multisector national initiatives underway in large-scale efforts throughout the US. All eight have at least five common elements: (1) attempt to address the determinants of chronic disease at a systems level by removing barriers to health-sustaining resources

humans require to thrive; (2) frame interventions to reduce inequities in health outcomes; (3) leverage funding from multiple sources; (4) identify policy drivers to achieve outcomes; and (5) require complex partnerships work together toward achieving shared goals. Additionally, given the potential for these live experiments to improve health outcomes for large populations, we believe these demonstration efforts are worth following to harvest the myriad lessons from which this bold body of social determinants of health work will derive.

Improving Food Access

In 2010, the US Department of Agriculture, working with the Departments of Treasury and Health and Human Services, established the Healthy Food Financing Initiative (HFFI) (Administration of Children and Families, 2017) to bring grocery outlets and other food retail establishments to urban, rural, and tribal communities with food deserts. Residents in these areas too often rely on fast food and convenience store options that provide an abundance of unhealthy food products. This work is important, because clear evidence shows correlations among availability of fresh produce in neighborhoods with concentrated fast-food outlets and nutrition (Gordon-Larsen, et al., 2006). Further research demonstrates that health consequences of the chronic diseases associated with such community conditions do not appear for decades (Cummins and Macintyre, 2006).



Synergy Between Community Development and Health

The Federal Reserve Bank of San Francisco and the Robert Wood Johnson Foundation created the Healthy Communities Initiative to stimulate more robust collaboration among community development, finance, population health and public health. The initiative creates innovative financing mechanisms as a means of promoting community development that can improve neighborhood conditions and health at the same time. The Federal Reserve Banks have provided financial support to local communities interested in bridging community development and health sectors. In the past eight years, participating leaders devel-

oped action strategies to create health by leveraging these sectors during more than 30 healthy communities conferences.

While community development and health often work in the same neighborhoods, they have not always actively collaborated. “This is starting to change, due in part to a growing recognition among health experts of the social, economic, and environmental factors that drive health outcomes” (Fazili, 2017, p. 1). These factors now serve as an underpinning for collective work between community development and health professionals. Research investigating the correlations between income and health outcomes also demonstrates that between 2001 and 2014, US residents with higher incomes lived longer and differences in life expectancy across disparate income groups increased (Chetty, et al., 2016). At the same time, life expectancy differences were shown to correlate with both health behaviors and local area characteristics (Chetty, et al., 2016). While more time is needed before we can assess the health benefits of these experiments, we do have clear evidence that health improves incrementally as a function of income level (Wilkinson, et al., 2003).

Leveraging Tax Policy to Identify Community Health Needs

The Internal Revenue Service (IRS) requires that all 2,900+ nonprofit hospitals direct a portion of hospital revenues on community benefit. A qualifying activity includes a community-wide needs assessment (every three years) and action plans to address needs identified by the respective communities. The IRS ultimately expects supported interventions to improve health status and wellbeing of residents in the service delivery area, engage multiple partners in implementation, and benefit those most at risk (National Academies, 2017); (IRS, 2014).

Since the agency established this requirement, partnerships across the nation have conducted thousands of community health assessments (NACCHO, 2017). Presently, 4,423 health providers are required to conduct health assessments, including 2,900 nonprofit hospitals and 223 accredited health departments and federally qualified health centers. Systematic evidence reviews show mixed results, and researchers cite the need for standardized criteria to guide hospital-based community benefit programming (Burke, et al., 2014). To address social determinants of health more consciously, some hospitals have reformulated their role as an “anchor institution,” enterprises that are rooted in their local communities by mission, invested capital, or relationships to customers, employees, and vendors.

Improving Environmental Conditions to Create Healthier Communities

The US Department of Housing and Urban Development established the Choice Neighborhoods program to leverage public and private sector funds to transform communities impacted by distressed public or HUD-assisted housing. Using a comprehensive approach to transformation, Choice Neighborhoods requires broad engagement of nearly all community sectors working toward revitalization goals, which include a focus on housing, people, and neighborhood. Importantly, these goals entail improving the quality of education available to residents (Bostic and Tate, 2011). Several studies demonstrate the program's effectiveness. Findings from HOPE VI, the predecessor program to Choice Neighborhoods, show increased property values, higher employment rates, reduced crime, increased availability of community support services, and improved health outcomes (Urban Institute and MDRC, 2015).

Build Capacity of Community-led Partnerships to Build Health

Led by a consortium of funding partners, BUILD Health is a private, nonprofit organization working to create a new norm in the US, by putting multi-sector, community-driven partnerships at the center of health to reduce health disparities caused by system-based or social inequity. The BUILD Health initiative aims to strengthen partnerships among community-based organizations, hospitals, health systems, health departments and other sectors to improve community health by working together on shared goals that address health challenges. BUILD stands for Bold, Upstream, Integrated, Local, and Data-driven. Nineteen community demonstration teams have recently begun implementation of strategies on a wide range of health threats, such as food insecurity, healthy eating, active living, and creating safer and less violent neighborhoods. This program has great potential because the investments being made in anchor institutions (such as the health departments, hospitals, schools, and other structures) that will remain serving their respective communities for years to come and the model focuses on wellbeing, not disease. The anchor institutions are assets that can pave the way for long-term capacity building for several generations.



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Improve Health by Removing Structural Barriers that Fuel Racism

Several noteworthy national initiatives provide opportunities to address the determinants of chronic disease by removing the obstacles to health-sustaining

resources humans require to thrive. One important initiative addresses segregation driven by public housing policy. HUD established the Affirmatively Fair Housing Rule (AFFH) to guide HUD grantees in reducing fair housing barriers in our nation's communities (HUD, 2015). The AFFH, a new legal requirement that guides an effective planning approach to reduce segregation, promotes fair housing choice, and creates discrimination-free communities, includes a fair housing assessment tool and data mapping resources. Effective implementation can transform racially and ethnically segregated communities living in poverty into places of opportunity.

Improve Health by Creating a Process to Address Interpersonal and Structural Racism

With a goal of eliminating racism within the US, W.K. Kellogg Foundation's Truth, Racial Healing & Transformation (TRHT) effort represents a groundbreaking body of work. "Our nation can no longer embrace it [racism] consciously or unconsciously. We do not want it to continue shaping our narratives or our communities, our economy or our democracy" (Christopher, 2016).



Since the launching of the TRHT in 2016, nearly 150 organizations across the spectrum of sectors, many with affiliates throughout the country, have become TRHT partners. Currently, there are 14 geographically and racially/ethnically diverse places engaged in TRHT activities, with the support of the Kellogg Foundation, other local foundations, and representatives from virtually every sector of each community. The TRHT framework guides action across five evidence-informed components: (1) narrative change; (2) racial healing and relationship building; (3) separation; (4) the economy; and (5) the law. This work helps communities create safe spaces for embracing racial healing and uprooting the belief in a hierarchy of human value that keeps us apart and limits opportunity:

Preventing Chronic Disease with Systems Approaches

Most public health challenges require multifaceted interventions. Chronic diseases are no exception. Effective problem solving involves using a systems lens and multi-sectoral approaches to: determine the nature of a problem; identify and test solutions; and evaluate results to identify opportunities for improvement using quality and performance improvement methods. Researchers and practitioners alike agree that the complexity of addressing the chronic disease drivers calls for a systems lens.

Systems thinking challenges health experts to understand the multiple systems (education, transportation, health care, housing, education, land-use planning) that contribute to health inequities and the interaction across subsystems. It can assist policymakers, clinicians and program delivery experts to find mutually reinforcing strategies that together would be more successful than any one on its own, as well as avoid policy development that undermines actions in other sectors (Braveman and Gottlieb, 2014); (National Academies, 2017). It allows people to map a longer chain of strategy impacts that go beyond their immediate focus, so that they can design interventions using frameworks that predict a multitude of outcomes, including unintended consequences. This model operates with the idea that the system itself is adaptive; it can change in response to external pressures or critical internal thought drawn from feedback loops. Results from these systems are not passive; they are related to decisions incorporated into structures (policies, laws, norms) that can perpetuate or break down inequities (Friel, et al., 2017).

Conclusions and Reflections for Action

The mounting evidence base for chronic disease drivers is instructive and provides important inferences for health advocates to reframe our approaches. In the US and around the world, research studies project the number of individuals living with chronic disease will increase significantly over the next two decades. Throughout the US, data show we are making important progress in advancing tobacco-free living as evidenced by declining smoking rates. We see additional progress on healthy eating and active living, but with significant inequities in outcomes. Chronic disease drivers from drug misuse and binge drinking are increasing. Zip code increasingly predicts life expectancy, and health outcomes improve as income levels rise.

Among the myriad implications of data presented here, several important trends influence how the US approaches chronic disease management and prevention, and we believe they merit significant attention. The first is our rapidly changing demographics vis-à-vis age and racial and ethnic demographic shifts, both of which signal increasing chronic disease. Second, the alarming increase in mental illness and its serious ramifications on chronic disease. Third, the US continues to lag behind many other nations in our disease burden, and we are missing opportunities to learn from the successes enjoyed by others globally.

While it is certainly true that all people require access to quality health care, research findings remind us that community context, income level, and race all matter more. The biomedical model has so much influenced our policies and ac-

tions that the predominant public discourse about health and wellbeing remains focused on the individual despite the evidence. As a nation of over 300 million people and growing, we must come to terms with the fact that society creates health, which means that we are manufacturing disease by design.

Achieving such a shift in consciousness about the creation of health will require Americans to change the nation's predominant narrative, which blames individuals suffering from the highest disease burdens to one more in line with scientific evidence. We must focus on systems changes and lift up the most promising strategies that directly address human needs. This narrative should inspire us to interrupt production of socially constructed health outcomes.

Reframing health must, therefore, provide robust support for eliminating racism in every community so that all human life is valued and supported. We have new tools and approaches to help groups build greater awareness of our unconscious biases, to learn how these insights can lead to a greater appreciation of our diversity, and to appreciate how we are all interconnected. We must also help communities remove structural barriers to racial equity and provide broad national support for this work to scale up. Eradicating racism and the belief in a human hierarchy of value must be a core component -- in every aspect -- of the work we do to improve the public's health. This is of paramount importance because the pattern of findings discussed herein makes clear that people of color and those society marginalizes based on fear and ignorance continue to exhibit greater disease burden for almost every health indicator.

We should invest in creative placemaking to spawn initiatives where public, private, not-for-profit, and community sectors partner to shape strategically the physical and social character of a neighborhood, town, tribe, city, or region around arts and cultural activities. These approaches have shown promise in the ability to clean away the residue of historical traumas and enhance natural resiliencies. So much of our funding sources narrowly target specific diseases. Incentivizing and supporting communities to reframe health may spawn an entire new set of solutions driven by people working together across many disciplines, much like what the Robert Wood Johnson Foundation is attempting with the culture of health framework (Robert Wood Johnson Foundation, n.d.). But communities need to lead the development of wellness models that will work for them.

We should redistribute resources from our expensive medical and social services systems and truly be flexible enough to support community-led capacity building efforts to meet the wellbeing needs of all residents. This will require us to invest in multi-sector, asset-based approaches much more seriously, and to

connect these efforts in more robust ways. The formation of a nationwide wellness network participating in a community of practice may result in surprising breakthroughs in truly constructing health and wellbeing. This will also provide a more robust learning function so that communities can share and inform each other's work. And it will require foundations and governments to braid resources so implementation teams have sufficient resources to be successful.

Finally, we should provide robust support to those implementing health interventions to incorporate systems thinking in as many efforts as possible so that the nation can learn from the outcomes of these experiments. National organizations can work together on a broad capacity building effort so that more sectors are applying systems approaches that support all aspects of our human needs.

We believe that health is the basis and, therefore, an essential ingredient of all human life. An emerging public health strategic agenda challenges us to create wellness for all. Let us apply what science tells us and embark on this journey together and inspire a new generation of people who intrinsically seek solutions to address human needs and produce healthier generations.

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Note: The content and ideas contained herein represent perspectives of the authors and do not necessarily reflect the official opinions of the National Network of Public Health Institutes or Wildflower Consulting, LLC.

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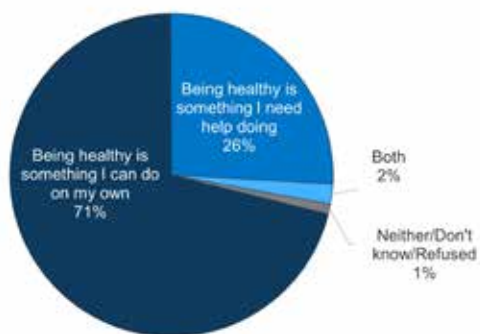
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Most Americans Say Being Healthy is Something They Can Do on Their Own, But 1 in 4 Say They Need Help

Please tell me which statement comes closer to your view, even if neither is exactly right:

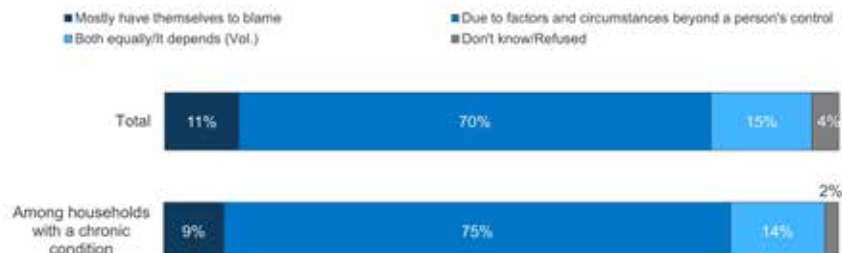


NOTE: Based on registered voters. Question wording modified. See topic for full question wording.
SOURCE: Robert Wood Johnson Foundation and Trust for America's Health Survey (conducted September 8-19, 2016)



About Seven in Ten Americans Say Chronic Disease Is Usually Due to Factors Beyond A Person's Control

In general, do you think people who have chronic diseases mostly have themselves to blame for their condition, or do you think chronic disease is usually due to factors and circumstances beyond a person's control?



NOTE: Question asked of half sample.
SOURCE: KFF Health Tracking Poll (conducted April 20-30, 2018)



"...all approaches to incentivize patients to control their own chronic diseases must undergo ethical analysis so that they can be designed to avoid significant harm. It means that we should suspend judgment about patients' moral responsibility to control their diseases and their care, encourage realistic notions of control and provide those low in activation with clinician support to meet their needs."

– BARBARA K. REDMAN, PH.D., M.B.E.

Ethical Issues in Responding to Chronic Diseases

Barbara K. Redman, Ph.D., M.B.E.

"... We still have a lack of understanding of the meaning and ethical implications of chronic illness in the lives of individuals, families and the broader society as well as a guiding vision of how a just and good society should accommodate the special needs of its chronically ill members, care for them and support them in their quest to live meaningful, satisfying lives." (Jennings, et al., 1988)

The health care system's response to the growing prevalence of chronic diseases raises significant ethical issues related to treatment, research and resource allocation. Overall, the response has been inadequate, with excessive reliance upon patient self-management and too little introspection by those in the health care sector regarding the systemic changes needed to orient care to meet these growing needs. Issues of environmental justice, some tools of public health practice, and certain financial incentives also play a role, often unacknowledged, in prevention and management of chronic diseases. Lacking a coherent response, the health care system remains at least neglectful, if not complicit, in tolerating less than adequate care for those with chronic disease.

Failure to Appreciate the Importance of Chronic Disease

Why, 30 years after Jennings et. al wrote the opening quotation, have we still not sorted out what is owed to the almost-all-of-us who at some point will have several chronic diseases? This issue will be with us for some time because chronic disease cannot, by definition, be cured. It is worth noting that neglect of chronic disease is a global problem, labeled as the social justice issue of our time (Horton, 2015). Causes have variously been ascribed to large corporations selling unhealthy products, pollution of the environment, medicine's preference for non-chronic disease work, inability of the bioethics community to specify the issues of justice involved, and apathy on the part of the public.

One could say that we have entered what is known in ethics as a maladaptive state of adaptive preference, in which an individual or society comes to accept things as they are (adapt to them), and to become resigned to them as the normal state of affairs even as they cause what should be acknowledged as unacceptable harm. In such a situation, it is essential to look at the incentives sustaining current practice and the ethical issues that remain unexamined or unsettled.

Despite much effort on the part of practitioners, particularly those in primary care, institutions in which care is embedded have failed to appreciate and respond to the importance of chronic disease; have tolerated a climate of unfairly blaming patients; and have neglected basic professional responsibilities such as producing and using an adequate evidence base. Matters of justice regarding who should get care are prominent in ethical discussions involving chronic diseases.

Several forms of justice are relevant for such an inquiry, especially ethical grounds for allocation of resources, which should reflect the human interests and priorities that are at stake (Rhodes, 2018), and for which there is broad endorsement. Throughout the literature on chronic disease there is evidence of allocation being framed in terms of: free-riding; efficacy; avoiding undue burden; attending to those with the most need; normal functioning and the importance of well-being (Rhodes, 2018). What combination of these is reasonable to guide our responsibilities in chronic disease?

Personal and Societal Responsibility

It is commonly believed that most individuals are personally responsible for behaviors such as smoking, overeating, and lack of exercise, which lead to increased risks of lifestyle diseases. In other words, individuals should be able to avoid and control their chronic diseases with lifestyle changes. This belief constrains what society owes that individual. Yet, genetic makeup (Wehby, et al., 2018) and certain social and environmental circumstances are widely seen as causal influences for chronic disease. In such a situation can one ever fulfill requirements for personal responsibility? Should individuals receive the stigmatization (Andersen and Nielsen, 2016) of being free riders?

In the face of this knowledge, societal attitudes and policies vary significantly. In Europe, an ethical value of solidarity -- shared commitment to carry "costs" to assist others -- acknowledges this situation, especially with the most vulnerable in a community, and affords them respect. In the United States, this value has played a marginal role, which is especially egregious because of the absence of direct

causal links between disease and lifestyle changes that are within an individual's control (Prainsack and Buyx, 2017). This means that some individuals will get sick no matter what they do and will need the help of others.

This backdrop of potential patient blame follows otherwise positive approaches to develop patient agency. For example, an approach called patient activation -- encouraging patients to develop the confidence and skills to manage chronic illness -- raises previously unexamined ethical questions. Does this approach ask patients to believe they are morally responsible for their health behaviors? Does patient activation make



patients vulnerable to blame, stigma and denial of health care resources if they are unable to reach desirable behaviors, or if they change the behavior but that does not resolve or positively affect the chronic disease? Since patient activation targets individual behavior, it ignores social determinants of health. It may imply that health should be the primary goal in life, leaving no room for patient choice to balance health with other life priorities. Patient activation can direct resources to those most easily activated and draw resources away from those who cannot attain it (Gibert, et al., 2017) because they do not have the educational skills or cultural background to challenge the health care system.

The example of patient activation shows how all approaches to incentivize patients to control their own chronic diseases must undergo ethical analysis so that they can be designed to avoid significant harm. It means that we should suspend judgment about patients' moral responsibility to control their diseases and their care, encourage realistic notions of control and provide those low in activation with clinician support to meet their needs (Gibert, et al., 2017).

What theories or frameworks of justice can guide allocation decisions? Justice between age groups has been supported by the view that health care resources should last a lifetime for each individual; thus, if they have used many resources in their younger years, fewer resources may be available as they reach old age even if they have increased needs from chronic disease. Such a view is based on the notion that all are treated equally over time. Objection to this perspective notes that life plans can be disrupted by disability or death or by negative cultural attitudes against old age (Jecker, 2013). An alternative is Nussbaum's (2006) capability approach which better reflects the positive frames for allocation. This approach maintains that justice requires each person, including those

in most need, regardless of age or disability, be sustained in each of their basic capabilities (life, health, affiliation, practice reason and control over their environment) at a threshold level required for human dignity and guaranteed by society. This approach acknowledges that even as the elderly experience higher rates of chronic illness, if needed, they should receive services to reach normal functioning and well-being.

Research on Chronic Disease

What we choose to treat or leave untreated, where research dollars are invested and how research subjects are approached, are normative (ethical) decisions. Unexplained treatment gaps for chronic diseases have been documented. For example, persons with end-stage chronic disease frequently do not receive palliative care (Chochinov, 2016). Why is rehabilitation for a chronic disease such as COPD successful in creating clinically relevant improvement in physical performance, shortness of breath and quality of life (Gloecki, et. al., 2018), but not for other chronic diseases that are stigmatizing, such as dementia where the benefit could be maintaining independence and avoiding functional decline (Cations, et al., 2018)? These two examples reflect unacknowledged forms of rationing based apparently on a lesser value being placed on the needs of those with chronic disease, and in particular for those conditions for which the pathology is not understood and treatment options are limited.

Currently, underinvestment in chronic disease research reflects a medical orientation to cure and not to the aggregate needs of the population. Some gaps are ethically very problematic – for example a systematic review of research addressing chronic pediatric pain found almost no studies of analgesic treatments and concluded that studies on this topic were of low methodological quality. Lack of diagnostic tools and of appropriate comparator groups were likely an important source of this gap (Boulkedid, et al., 2018). A second example of a serious research gap is how limited health literacy affects patients' ability to manage chronic low back pain, which is very common in US adults (Edwards, et al., 2018). A third is the well-known exclusion of older individuals with their accumulation of chronic diseases from clinical trials. A summary of evidence shows that one-third of trials, including for diseases common in older populations, exclude older individuals, often for no stated reason. Despite the oft-stated rationale that other health problems complicate isolation of treatment effects, this population is entitled to evidence-based treatments tailored to their needs and physiology (Thake, 2017).

Research in some chronic diseases carries particular ethical risks. Diseases for which there is a long history of failed attempts to understand it or its treatment (as is the case with many chronic diseases) often yields vulnerability to the therapeutic misconception that it is worthwhile to pursue any clinical trial or unproven treatment with even a hint that it might work. Patients in these circumstances can easily be exploited. Studies of chronic diseases that carry stigma, primary prevention of schizophrenia for example, are ethically complex in part because of the significant potential adverse effects of incorrectly estimating risk (Appelbaum, 2015).

Gaps in the evidence base to support chronic disease are ethically problematic because they lead to patient blame and devaluation. A positive approach to chronic disease management requires an active program of patient capability development (skills in managing their health). Here we turn to patient self-management, which has become a hallmark of chronic disease management.

Treatment of Chronic Disease

Much of the current health system infrastructure is still based on communicable disease and acute care and has never adjusted to those expected not to be cured. Primary care and public health have made this shift more than have acute- and hospital-based systems of care, still thought to exist to correct pathology. Rather than a full-fledged system redesign for chronic disease, the focus became educating patients for patient self-management (PSM) and to some extent, incentivizing primary care providers to care for them. Accompanying PSM has been a focus on adherence to medical management recommendations and lifestyle control, too often accompanied by implied or explicit blame that the patient did not self-manage well enough to control disease progression (Thorne, et al., 2016).

Lack of a structural redesign of a health care system to optimally deal with chronic disease was accompanied by retention of provider authority with the expectation that patients would self-manage (SM) as the provider prescribed. Patient progress was measured by biological and disease control outcomes alone (Morgan, et al., 2017)

and not by patient-centric outcomes. In contrast, persons with chronic disease should be seen as assets and as active co-producers of health and well-being.



Ascendance of a political philosophy based on neo-liberal values holds that people should be held accountable for their contributions to society and for costs they incur. This implies a moral responsibility for good health. Congruent with this philosophy and in the face of budget constraints, significant professional health care costs of monitoring and managing chronic disease have been diverted to patient and family self-management, but without patients' and families' adequate preparation and ability to absorb this work and these costs.

Tasks and judgments required of patients to manage chronic disease themselves vary by disease and by social circumstances but include monitoring of symptoms and biological measurements; administering and in some cases titrating treatment; contacting providers appropriately in times of crisis; and managing social, emotional and financial aspects of chronic disease. Complexity varies widely from, for example, management of chronic heart failure, in which patients are frequently cognitively impaired, to management of blood pressure control on a largely preventive basis. Frequently, patients simultaneously manage multiple chronic diseases, often with conflicting demands in their regimens. PSM education and support may or may not be offered by providers as part of care. They are sometimes incorporated into hospitalizations or, rarely, in community-based programs; are very intermittently available; and very rarely come with documented evidence of how competent or confident patients are to undertake the self-management expected of them.

This mandatory delegation to patients without professional assurance that they are competent and safe to do so violates basic ethical responsibilities (Redman, 2007). Yet, health professionals operate in a system that doesn't allow them the time or resources to assure that patients are capable of safe SM. Some providers experience this situation as a moral dilemma creating moral distress.

There are several elements to this problem. First, there has been little investment in systematic development of definitions and well-validated tools by which to produce an evidence base for PSM support. Mean follow up of studies of PSM is only 1.5 years, very few trials include patients with co-morbidities or diabetes complications, and ideal characteristics of PSM support are unknown, although current studies indicate longer (more than 10 hours) and repeated PSM preparation are more beneficial (He, et al., 2017). These studies are short-term and their findings ambiguous. They do not address what support patients need over the many years they will be dealing with chronic disease(s). No entity is taking leadership to improve the quality of diabetes PSM measurement tools of which there are many, usually designed by investigators with measurement characteristics rarely tested, used only in single studies and often neglecting outcomes of most importance to

patients. Lacking these basics for building an evidence base, it is not possible to improve practice (Packer, et al., 2018) or to determine the value of PSM support and to invest health system resources in it. On their face, these interventions intend to produce good. But lack of documented efficacy can be a form of deception, leading patients to think they are prepared to manage their own care.

Second, safety is inadequately studied. In addition to not knowing if combinations of multiple drugs given chronically are safe (Garatinni and Bertelev, 2018), we have little idea if PSM is safe and for whom. Studies of individuals with COPD show that avoiding an exacerbation saves money and slows deterioration from the disease. But it is clear that only a subset of patients can be taught to adequately self-manage and that others can be harmed by trying to do so. In contrast, those with hypertension who self-monitor blood pressure with active support showed improved control (Tucker, et al., 2017).



Third is the obsession with patient non-compliance with the prescribed regimen, ignoring the fact that some non-compliance is intelligent or is unintended. Multiple errors in the chain of provider logic may also occur: Research on which treatment is based may be irreproducible or the findings may not apply to a particular patient; toxicity of drugs is understudied; providers may be making mistakes or caught in clinical inertia; and practice guidelines may be biased toward particular commercially-available treatments. It is important to note that no overall evaluation of the quality of medical care in chronic disease or even in individual common chronic diseases could be located, reinforcing the notion that the importance of this care is low. Lack of what should be an expected evidence base also makes it difficult to sort out errors made by providers from those made by patients as they managed their own care.

While financial incentives for patient compliance have so far not been effective (Van Epps, et al., 2018), a treatment regimen that works is strongly related to patient satisfaction (Coventry, et al., 2014). Studies have shown that prescription filling (one element of compliance) can be predicted from claims data (not generally available to practitioners) and less so from medical records (Roebuck, et al., 2018); (Franklin, et al., 2018), thus providing an opportunity to identify individuals for whom a compliance assessment would be helpful.

Fourth, although they cannot be thought to be representative of all care, countless studies show that many practitioners and health care systems do not have the skills or time to support patients in self-management (Chatterjee, et al., 2018). While much evidence comes from the UK and parts of Europe where the notion of “Expert Patient” was incorporated into policy, studies find patients quite different from this image – they are instead weary from life stresses and struggling with providers over issues of compliance and control (Francis, et al., 2018). Patients are not capable of self-management on their own, especially with the burden of multimorbidity. The amount of work patients are expected to undertake, often uncoordinated across various medical providers, is vastly understudied. Patients want a partnership with providers, to work with them as they try new self-management strategies. Learning is a prolonged process, accompanied by frustration, depression and anxiety. Professionals working with these patients need the time and skills to address these issues and to feel that they have met their ethical responsibilities to persons with chronic disease.

Instead, providers tend to inform patients and focus only on medical aspects of self-management and neglect emotional aspects and how managing the disease(s) affects patient ability to fulfill their social roles. Health care systems fall below attainable standards in ways that are preventable, such as one-quarter of discharged patients being readmitted to hospital, in part because of inadequate assessment of their ability to carry out self-management (Auerbach, et al., 2016); (Zafar, et al., 2017). Indeed, a review of studies of the chronic care model developed in the 1990s to address chronic disease in primary care found few studies focusing on patient-centered outcomes and none mentioned patient work, even though most patients now present with multimorbidities and increased psychosocial complexity (Boehmer, et al., 2018).

Another form of injustice relevant to PSM of chronic disease is epistemic injustice – a systemic lack of opportunity to acquire knowledge one needs because of the epistemic structure of how a society is organized. Institutions, including health care, have a crucial role in the distribution of knowledge and in assuring that people (patients and families) have the capability to assimilate what is disseminated (Kurtulmus and Irzik, 2016). Epistemic injustice can also reveal itself when patients’ experiences, such as chronic pain, are downgraded, ignored or rejected.

Several technologies and philosophies offer new and more positive perspectives about chronic disease. Big data (high volume, high diversity, biological, clinical and informational) analytics offer improvements in risk prediction, diagnostic accuracy, prediction of hospital readmission and cost reduction by analyzing text-

based health documents and data through predictive modeling. For example, patient deterioration too subtle to observe, including COPD exacerbation, can be detected with this approach (Bhardwaj, et al., 2018). Also, wearable devices measure blood pressure, heart rate, sugar levels, oxygen levels, and body temperature, but can produce errors and raise privacy risks. If these issues are addressed, they can support independence for persons with chronic diseases.

Chronic disease can offer a growth experience, even coexist with distress, and focus on an outcome goal much broader than compliance with the medical regimen. Problem-focused and optimistic coping, family and social relationships predict growth even in the midst of trauma from a chronic disease (Dirik and Gocek-Yorulmaz, 2018). Adaptive capacity and balancing life priorities are appropriate substitutes for compliance and control. Few studies have explored what it means to people to control and manage their chronic illnesses, addressing their shifting sense of mastery as disease and life situations change (Heaton, et al., 2016).

Environmental Health, Public Health and Financial Incentives

Perhaps the basic ethical concern is how patients and clinicians are increasingly made responsible for reversing the influence of other determinants of health. This mis-attribution locks them into a blame-placing relationship, and often a sense of failure (Thille, et al., 2014). Here we look at environmental, public health and financial incentives that are essential to chronic disease prevention and control and to positive relationships with patients and communities.

Environmental issues and their impact on chronic disease are widespread, frequently uncontrolled and are the basis of environmental injustice. Surveillance of community-level lead exposure should be improved. Endocrine-disrupting chemicals in water, soil and air, especially common in low-income populations, are not directly regulated to decrease the risk of diabetes. Commonly alleged factors of obesity and physical inactivity explain less than one-third of the risk of diabetes; environmental factors clearly have an incompletely understood impact (Shaikh, et al., 2017). Better documented is the effect of abandoned mines on Native American tribal lands, leaching harm-



ful chemicals and metals into water, soil and air and linked to cancers and neurological disorders (Lewis, et al., 2017). A positive step would be entering data on social and environmental conditions into the electronic health record and effectively addressing them directly, although consensus on standards for doing so do not yet exist (Cantor and Thorpe, 2018).

Public health secures basic systems that promote population health with special emphasis on oppressed people. Yet, one of its tools for the past quarter century has been campaigns focused on behavior change, highly contentious in both goal and method. Fear-based campaigns, such as those related to tobacco use, can be said to draw individuals' attention to risks of certain behaviors and to enhance their ability to choose, but they also may shame and stigmatize and fail to address the social conditions that contribute to chronic disease (Bayer and Fairchild, 2016). Friesen (2018) notes that personal responsibility is emphasized for highly stigmatized behaviors (e.g. alcohol, obesity) but not for poor health outcomes that arise from socially-approved behavior (e.g. chronic brain injury from playing football).

Public policy with financial incentives to control so-called lifestyle causes of chronic disease should be informed by empirical findings. For example, Friedman and colleagues (2016) note that allowance of health insurance surcharges on tobacco users' premiums did not affect smoking cessation and violated a basic purpose of the *Patient Protection and Affordable Care Act* (ACA, 2010), which is to provide individuals with protection from high health care costs. Instead, it had the ef-



fect of discouraging enrollment by persons with high-cost conditions (Friedman, et al., 2016). Ethical analysis would ask why tobacco use was singled out from other behaviors. It is important to note that although individuals of lower socioeconomic status in one state responded disproportionately to tobacco taxes by making moves toward smoking cessation, their efforts were not sustained (Parks, et al, 2017), leaving them further disadvantaged economically and unsuccessful in quitting. Better understanding of such financial incentives is important.

US health policy has historically permitted charging those with chronic diseases more for health insurance, representing an unwillingness to incorporate their extra costs, but continuing to do so in the context of the *Patient Protection and Affordable Care Act* (ACA, 2010) may be a corruption of the law's purpose. Coverage gains for adults with chronic conditions (higher among Marketplace than non-Marketplace enrollees) (Karpman, et al., 2018) simply reflects prior exclusion policies that were accepted as ethical. It does not, however, disrupt commercially-derived profits which are arguably a more potent cause of chronic disease than are individual weaknesses to adopt their products.

Many face other financial barriers to the management of their chronic disease(s). It is important to note the financial burdens for those living at poverty levels - high deductibles for maintenance medications, costs from tobacco and sugar taxes, etc. For these populations, social conditions such as homelessness or housing instability seriously interfere with personal energy, storage of medication and testing equipment, limited food choices and money necessary to manage their diabetes (Keene, et al., 2018) or other diseases.

Incentives that target disadvantaged populations, particularly for behavioral change, can be a positive way to decrease unfair inequality in health. They are, however, ethically problematic if individuals cannot afford to decline an incentive even if they would not consider it in their best interest, or if the incentive sends a message of unequal social status, is stigmatizing or marks these populations as irresponsible (Voight, 2017). Poor individuals often do not have choices that fit their circumstances.

Supporting Patients with Chronic Conditions

In addressing the health care system's ability to care for chronic disease, it is important to ask whether it has, perhaps inadvertently, become complicit in failing to appreciate the importance of chronic disease. Is the system not fairly allocating resources to prevent or decrease chronic illness? Is it not producing better outcomes of importance to patients and asking families and patients to do too much?

It must first be noted that a comprehensive evaluation of chronic disease care could not be located. The evidence that is available and cited above suggests some indifference within the health care system to adequately address important elements of chronic disease care. Does this rise to the level of complicity, in which one entity contributes to another entity's wrongdoing? While the Hastings Center Report quote at the beginning of this paper suggests that society should decide how those with chronic disease should be treated, those designing and operating the health system and those producing its scientific base have professional responsibilities to provide care that is efficacious and safe, and should reflect the increasing patient-centeredness evident in at least some recent public policy.

If the health care system is a potential wrongdoer, are the health professionals that form the workforce complicit in areas of essential care, such as chronic disease, that are systematically underdeveloped? Do health professionals have a duty to challenge health system policy and practice contributing to this underdevelopment? A claim of complicity is judged by how proximate, reversible or frequent the contribution was and whether the wrongdoing purpose was shared (Lepore & Goodin, 2017). Because there is little direct evidence that those designing and providing care to patients with chronic disease intended to deliver suboptimal care to persons trying to self-manage, strong complicity is unlikely. Indeed, providers could not abandon patients even though working conditions rarely gave them enough time and resources to meet these patients' needs, but they are morally responsible to push for resources to do so. Ultimately, knowledge that care is substandard and that one's actions contribute to it qualifies as a minimal form of complicity.

An implicit authority seems to have set priorities favoring acute care, making these preferences seem normal and inconsequential accompanied by a diffusion of responsibility (Passini, 2017) that renders no one responsible for the life-long care that will optimally manage the disease but also sustain or restore optimal functioning and well-being. Listen to our language and practices: People with chronic disease could have avoided it if they had chosen to live differently. It is the patient's responsibility to manage her own care; chronic disease needs only intermittent treatment adjustment which the patient has only to follow.

How do we approach the overwhelming need for patients to do much of the work to manage chronic disease while assuring they are competent to do so and are supported?

- Invest in common definitions and research that will systematize the evidence base and be viewed as fair. An example of individuals with serious mental illness is instructive. These individuals die up to 25 years prematurely and have significantly higher odds of a range of chronic medical conditions for which treatment, including PSM for both medical and psychiatric care, has not been addressed. A review of the few studies that do exist found that integrated psychiatric and medical interventions have been successful and should be extended. But the fact that these studies used more than 70 different measurement instruments precluded a meta-analysis of the accumulated findings (Whiteman et al., 2016) and therefore the adequacy of the evidence base.
- Treat chronic disease as itself a health disparity as well as for some groups within it. Use interventions and measures that directly target disparities; include equity as a domain of performance measurement; use value-based payment; and build partnerships to address factors outside the direct control of the health care system (Anderson, et al., 2018).
- Redesign the health system using a capability approach. Although theories of justice and their indicators, identified earlier in the paper, are idealizations, they offer perspective about what is right. Chronic disease literature on the just allocation of care engages with free-riding (not taking responsibility for one's health), but far less on avoiding undue burden, attending to those with the most need, and normal functioning and well-being (Rhodes, 2018), all of which are central to chronic disease management. Heavy focus on biological outcome measures confirms a commitment to a narrow medical view. If used, the capability approach attends to those most in need and supports capabilities needed to be learned for normal functioning.
- Perhaps developing a dedicated service of nurses with documented skills and wide availability to all persons with chronic diseases is a start. This service should also document patient needs, test tools and become an advisory unit for development of the evidence base that is necessary to professionalize the service. Liaison with social and legal services should document social and environmental factors contributing to chronic disease and test policy and advocacy approaches to reverse those practices detrimental to health.

Conclusion

The dominant ethical issue reviewed in this paper is the lack of a strategic, effective approach for addressing research and treatment for chronic disease – incredible considering the size of the issue and its impact. Shifting of both blame and responsibility to patients, failure to study and establish approaches that meet their needs, and tolerance of poor research methodology have all been described. All of these issues are correctable, but apparently not in the current health care system and perhaps through the political institutions setting terms for its structure and function.

This leads to the question: What is needed for a representative deliberation to reach some level of consensus which has been evading us since it was documented in the 1980s by a Hastings Center report (Jennings, et al., 1988)? There still appears to be a dramatic imbalance of power between patients and the health care system, modest movement from the normative framework of patient responsibility for lifestyle control and compliance with the medical regimen, and strong preference for biological over social outcomes.

The history of our collective moral learning requires that we reject some of our current practice and its structure, which we have come to believe is wrong (Aphiah, 2017). We have not yet arrived at this point for chronic disease. We should know now what changes are feasible, given the social structures in which they are embedded, understanding that the ideal may not yet be feasible. The most sensitive moral issues to be addressed are unfairly blaming patients and not providing the support they need to successfully self-manage after a serious effort to develop the skills they need to do so. Broad societal discussion of these issues is necessary, while simultaneously being aware of “adaptive preference,” a resignation to accepting the system as it is. Our recent turn to the benefits of a learning health care system should be extended to patients, especially those with chronic disease, who also must be helped to learn.

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P R E V E N T I O N

I S B E T T E R

T H A N C U R E

REDUCING THE BURDEN OF CHRONIC DISEASE

A Report of the Aspen Health Strategy Group

The mission of the Aspen Health Strategy Group is to promote improvements in policy and practice by providing leadership on important and complex health issues. The group is comprised of 24 senior leaders across influential sectors including health, business, media, and technology, and is part of the Health, Medicine and Society Program at the Aspen Institute. Co-chaired by Kathleen Sebelius and Tommy G. Thompson, both former governors and former US Secretaries of Health and Human Services, the Aspen Health Strategy Group tackles one health issue annually through a year-long, in-depth study. This book is a collection of papers on the group's third subject: prevention of chronic disease. The papers address topics related to the financing, services and ethical issues related to chronic disease, and includes a final consensus report based on the group's work.



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