Elealth Reforms

Help for Americans with Pre-Existing Conditions

Health Reform: Help for Americans with Pre-Existing Conditions

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Introduction

n March, the President signed an historic package of health reforms into law. The new law offers critical protections for the millions of Americans who have pre-existing conditions today—as well as for those who are healthy now but who may develop a health problem as they grow older. As a result of health reform, no American with a pre-existing condition will be denied coverage, charged a higher premium, or sold a policy that excludes coverage of essential health benefits simply because he or she has a pre-existing condition.

This report takes a closer look at the number of Americans with *diagnosed* pre-existing conditions who, absent reform, would be at risk of being denied coverage in the individual insurance market. The uninsured and those who do not have access to job-based coverage are at greatest risk, but even those who now have coverage at work could be at risk if they lose or leave their jobs and have to find coverage in the individual market. To better understand the effect that health reform will have on these people, Families USA commissioned The Lewin Group to quantify the number of Americans who are diagnosed with conditions that commonly lead to denials of coverage.

Looking only at those serious conditions that are commonly linked to coverage denials, we found that 57.2 million non-elderly Americans have a pre-existing condition that could lead to a denial of coverage in today's individual insurance market. That's more than one out of every five people under the age of 65, or 22.4 percent. No group is immune to the effects of this pervasive problem: It affects people in all age groups, every racial and ethnic group, and every income group. All of these people with diagnosed pre-existing conditions are at risk for being denied coverage.

Our analysis does not include every condition that may lead to a denial of coverage, nor does it capture every person with a pre-existing condition that would likely result in higher premiums or excluded benefits. Further, this analysis cannot capture the uninsured and underinsured Americans who, lacking a way to pay for care, do not seek treatment and whose health conditions, therefore, remain undiagnosed. Because people with low incomes and racial and ethnic minorities are disproportionately represented among the uninsured and underinsured, they are likely to be undercounted in our analysis.

The protections that health reform offers mean that every American will now have greater security and peace of mind, knowing that insurance companies will be required to sell health insurance to all individuals regardless of their health status, to charge them the same premiums rather than making them pay more, and to cover all benefits. These new protections mean that every American will always be able to purchase quality, affordable coverage.

Summary of Methodology

This report examines the number of Americans with diagnosed pre-existing conditions who, absent reform, would be at risk of being denied coverage in the individual insurance market. To better understand the magnitude of this problem, Families USA commissioned The Lewin Group to analyze data relating to pre-existing conditions. As described more fully in the Technical Appendix on page 15, The Lewin Group quantified the number of Americans who are diagnosed with health conditions that commonly lead to denials of coverage in today's marketplace. This study's findings are based on data on health conditions from the U.S. Agency for Healthcare Research and Quality's Medical Expenditure Panel Survey (MEPS) and demographic data from the U.S. Census Bureau's Current Population Survey (CPS). This analysis presents the total number of non-elderly, non-institutionalized, non-Medicare-eligible Americans who are diagnosed with pre-existing conditions that commonly lead to a denial of coverage, including those who currently have health insurance but would be at risk if they needed to seek coverage on their own in the individual insurance market.

Key Findings

One in Five Americans Is at Risk of a Denial of Coverage

- Approximately 57.2 million Americans under the age of 65 have a pre-existing condition that, absent reform, could lead to a denial of coverage by an insurance company (see Table 1).
- This means that, without health reform, more than one in every five non-elderly Americans (22.4 percent) is at risk of being denied coverage.

People under Age 65 Diagnosed with a Pre-Existing Condition that Could Result in a Denial of Coverage

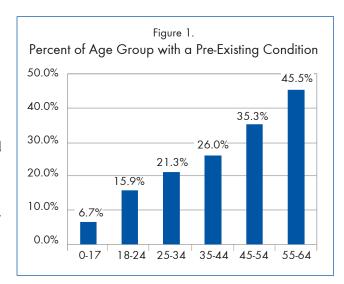
Population Under 65*	Population under 65 with a Pre-Existing Condition	Percent of Population under 65 With a Pre-Existing Condition		
255,103,000	57,152,000	22.4%		

^{*} Data are for the non-institutionalized, non-Medicare-eligible population.

Source: Estimates based on pre-existing conditions diagnosed or treated in 2007, prepared by The Lewin Group for Families USA (see the Technical Appendix for details).

Pre-Existing Conditions: A Problem that Grows with Age

- Individuals in every age group are affected by pre-existing conditions that, absent reform, could lead to a denial of coverage (see Figure 1 and Table 2). However, those who are older are much more likely to have such a condition, as follows:
 - Nearly one in six young adults aged 18 to 24 (15.9 percent) has a pre-existing condition that could lead to a denial of coverage.
 - More than one-third of adults aged 45 to 54 (35.3 percent) have a pre-existing condition that could lead to a denial of coverage.
 - More than two in five adults aged 55 to 64 (45.5 percent) have a preexisting condition that could lead to a denial of coverage.



People under Age 65 Diagnosed with a Pre-Existing Condition that Could Result in a Denial of Coverage, by Age

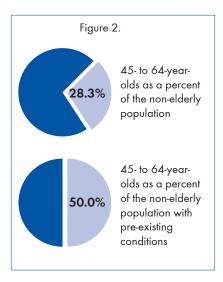
Age Group	Number in Age Group*	Number in Age Group with a Pre-Existing Condition	Percent of Age Group with a Pre-Existing Condition	As a Percent of Non-Elderly People with a Pre-Existing Condition
0-17	73,793,000	4,952,000	6.7%	8.7%
18-24	28,298,000	4,486,000	15.9%	7.8%
25-34	39,667,000	8,460,000	21.3%	14.8%
35-44	41,167,000	10,696,000	26.0%	18.7%
45-54	42,085,000	14,863,000	35.3%	26.0%
55-64	30,092,000	13,695,000	45.5%	24.0%
Total**	255,103,000	57,152,000	22.4%	100.0%

 $^{^{}st}$ Data are for the non-institutionalized, non-Medicare-eligible population.

Source: Estimates based on pre-existing conditions diagnosed or treated in 2007, prepared by The Lewin Group for Families USA (see the Technical Appendix for details).

^{**} Numbers do not add to total because of rounding.

- Adults aged 45 to 64 account for only 28.3 percent of the non-elderly U.S. population, but they make up fully half (50.0 percent) of those with pre-existing conditions (see Figure 2).
 - This phenomenon is most pronounced among adults aged 55 to 64. Adults in this age group account for only 11.8 percent of the non-elderly U.S. population, but they make up nearly a quarter (24.0 percent) of those with pre-existing conditions.



Children and Young Adults with Pre-Existing Conditions

- While the percentage of American children and young adults who have a pre-existing condition that could lead to a denial of coverage is low relative to older Americans, a substantial number of children and young adults are affected.
 - Nearly 5.0 million children under the age of 18, and 4.5 million young adults aged 18 to 24, have a pre-existing condition that could lead to a denial of coverage.

Every Income Group Is Affected

- People of every income group have pre-existing conditions that, without health reform, could lead to a denial of coverage (see Table 3). By income group, we see the following trend:
 - The lowest-income Americans are the most likely to have such a condition, with nearly one-quarter (24.2 percent) of individuals in families with incomes below 100 percent of the federal poverty level (less than \$22,050 for a family of four in 2010) affected.
 - Approximately 21.9 percent of individuals in families with incomes between 100 and 199 percent of poverty (\$22,050-\$44,100 for a family of four in 2010) have such a condition.
 - Approximately 22.2 percent of individuals in families with incomes at or above 200 percent of poverty (more than \$44,100 for a family of four in 2010) have such a condition.
 - While the lowest-income Americans are slightly more likely to be affected by pre-existing conditions, middle-income and higher-income Americans (those in families earning more than 200 percent of poverty, or \$44,100 for a family of four in 2010) make up more than two-thirds (69.8 percent) of those with pre-existing conditions that could lead to a denial of coverage.

People under Age 65 Diagnosed with a Pre-Existing Condition that Could Result in a Denial of Coverage, by Income

Family Income Relative to the Federal Poverty Level	Number in Income Group*	Number in Income Group with a Pre-Existing Condition	Percent of Income Group with a Pre-Existing Condition	As a Percent of Non- Elderly People with a Pre-Existing Condition
<100%	32,832,000	7,932,000	24.2%	13.9%
100-199%	42,653,000	9,336,000	21.9%	16.3%
≥ 200%	179,618,000	39,884,000	22.2%	69.8%
200-399% ≥ 400%	78,291,000 101,326,000	1 <i>7</i> ,408,000 22,4 <i>7</i> 6,000	22.2% 22.2%	30.5% 39.3%
Total**	255,103,000	57,152,000	22.4%	100.0%

^{*} Data are for the non-institutionalized, non-Medicare-eligible population.

Source: Estimates based on pre-existing conditions diagnosed or treated in 2007, prepared by The Lewin Group for Families USA (see the Technical Appendix for details).

Every Racial and Ethnic Group Is Affected

- People of every racial and ethnic group have pre-existing conditions that, absent reform, could lead to a denial of coverage (see Table 4 on page 6). By race and ethnic group, we see the following trend:
 - American Indians and Alaska Natives are the most likely to be affected, with more than one-quarter (25.9 percent) having a pre-existing condition that could lead to a denial of coverage.
 - Approximately one-quarter (24.4 percent) of whites (non-Hispanic) have such a condition.
 - Nearly one-quarter (23.4 percent) of African Americans (non-Hispanic) have such a condition.
 - More than one in six Hispanics (16.9 percent) is affected.
 - Slightly fewer than one in six Native Hawaiians and other Pacific Islanders (14.5 percent), and just over one in 10 Asian Americans (11.7 percent), have a pre-existing condition that could lead to a denial of coverage.

^{**} Numbers do not add to total because of rounding.

Table 4.

People under Age 65 Diagnosed with a Pre-Existing Condition that Could Result in a Denial of Coverage, by Race or Hispanic Origin

Racial or Ethnic Group	Number in Group*	Number in Group With a Pre-Existing Condition	Percent of Group With a Pre-Existing Condition	As a Percent of Non- Elderly People with a Pre-Existing Condition
American Indian/Alaska Native	3,400,000	880,000	25.9%	1.5%
Asian	12,433,000	1,454,000	11.7%	2.5%
Black, non-Hispanic	31,851,000	7,452,000	23.4%	13.0%
Hawaiian/Pacific Islander	910,000	132,000	14.5%	0.2%
Hispanic	42,809,000	7,221,000	16.9%	12.6%
White, non-Hispanic	163,699,000	40,012,000	24.4%	70.0%
Total**	255,103,000	57,152,000	22.4%	100.0%

^{*} Data are for the non-institutionalized, non-Medicare-eligible population.

Source: Estimates based on pre-existing conditions diagnosed or treated in 2007, prepared by The Lewin Group for Families USA (see the Technical Appendix for details).

Our analysis is based on the number of Americans who are *diagnosed* with a pre-existing condition that could lead to a denial of coverage. The analysis did not control for disparities in access to care and in the delivery of care that may result in lower rates of diagnosed disease among certain racial and ethnic minority groups. For a more in-depth examination of this point, please see the Discussion below.

Discussion

Millions of Americans have pre-existing conditions, such as diabetes, heart disease, and cancer. These people will be substantially helped by the new health reform law. Under health reform, insurance companies will no longer be allowed to deny people coverage based on their health status. Equally important, insurance companies will no longer be allowed to charge higher premiums for this coverage or to sell policies that exclude coverage for certain benefits based on a person's pre-existing condition.

This study was designed to improve our understanding of how many Americans have preexisting conditions that could lead to a denial of coverage by an insurance company if there were no protections for people with pre-existing conditions. Our report looks at people who are diagnosed with health conditions that commonly lead to denials of coverage. Denials, however, are just the tip of the iceberg. Our analysis presents a conservative estimate of the number of people who are affected by pre-existing conditions for the following three reasons:

^{**} Numbers do not add to total because of rounding.

- First, the data capture only the number of people who were *diagnosed* with one of a list of specific pre-existing conditions; it does not count people who had an undiagnosed condition.
- Second, the data count only those people who were diagnosed with or treated for one of a list of pre-existing conditions within the one-year period of 2007 (the latest year for which data are available).
- Third, we count only people who had at least one health condition on the list of specific conditions that are likely to lead to a denial of coverage. We do not count people who had conditions that are not on this list but that may also lead to a denial of coverage or to higher premiums or coverage exclusions.

The findings of our analysis are alarming: 57.2 million non-elderly Americans—more than one out of every five people under the age of 65 (22.4 percent)—have a pre-existing condition that, absent reform, could lead to a denial of coverage.

A Shared Problem

Our findings demonstrate that every group of Americans—people from every age group, income group, and racial and ethnic group—have pre-existing conditions. While people of all ages are affected, our analysis found that the likelihood of having a pre-existing condition grows with age. Older adults are more likely than children and younger adults to have a pre-existing condition that could lead to a denial of coverage in today's marketplace. For example, fewer than one in five young adults aged 18 to 24 (15.9 percent) has a pre-existing condition that could lead to a denial of coverage, while more than two in five adults aged 55 to 64 (45.5 percent) have such a condition. In addition, adults aged 45 to 64 account for only 28.3 percent of the non-elderly U.S. population, but they make up half (50.0 percent) of those with pre-existing conditions.

Our findings also reveal that every income group experiences the effects of this widespread problem. For instance, the lowest-income Americans are the most likely to have such a condition, with nearly one-quarter (24.2 percent) of individuals in families with incomes below 100 percent of the federal poverty level (less than \$22,050 for a family of four in 2010) affected, but middle- and higher-income Americans face pre-existing conditions nearly as frequently. More than one in five Americans (22.2 percent) in families earning more than 200 percent of poverty (more than \$44,100 for a family of four in 2010) has a pre-existing condition that could lead to a denial of coverage.

Finally, the findings show that every racial and ethnic group has pre-existing conditions that could lead to a denial of coverage. In fact, approximately one-quarter (24.4 percent) of whites (non-Hispanic) and 23.4 percent of African Americans (non-Hispanic) have such a condition, while slightly more than one in six Hispanics (16.9 percent) is affected.

While these findings may seem somewhat counterintuitive, our analysis looks only at those people who have been *diagnosed* with a pre-existing condition. Research indicates, however, that there are substantial disparities in access to care and the delivery of care across racial and ethnic groups, which may in turn lead to differing rates of diagnosis. For example, Hispanic adults are more than twice as likely as non-Hispanic adults (34.3 percent versus 15.9 percent) to lack a usual source of care, and more than a quarter (25.2 percent) of Hispanic adults had no health care visits in 2007, compared to 14.7 percent of non-Hispanic adults. Similar trends can be seen in the delivery of cancer screenings: Only 37.3 percent of Hispanic adults over age 50 and 48.6 percent of African American adults over age 50 received colorectal cancer screening in 2005, compared to 58.5 percent of white (non-Hispanic) adults over age 50.²

Current Insurance Company Practices

Until now, health insurers have generally been free to treat individuals with pre-existing conditions unfairly. In most states, insurers have been able to refuse to sell individuals policies due to a variety of factors, including their medical history, health status, and health risks. For instance, a person with a health condition such as diabetes could be denied coverage in the individual market because of his or her pre-existing condition.³ While our analysis looks only at those who are at risk of being denied coverage due to a diagnosed pre-existing condition, still more people may be denied coverage because they are at risk for developing such a condition. For example, people may be denied coverage if they take common drugs for arthritis, cholesterol, or other health conditions, even if they are taking them to *prevent* a disease from developing and have not actually been diagnosed.⁴

If people with pre-existing conditions find an insurer that is willing to sell them a policy, in most states, insurers can charge them exorbitant premiums based on their pre-existing conditions.⁵ Currently, in the majority of states, there are no limits on how much an insurance company can vary premiums based on an individual's health status.⁶ This means that insurance companies have free rein to set premiums at whatever level they claim is "necessary." Practices like these make health insurance unaffordable for millions of Americans.

Even if people with pre-existing conditions pay these very high premiums for coverage, the insurance policy they get still might not cover their most important health problems. In every state, most insurance companies can exclude coverage for care related to enrollees' pre-existing conditions, at least for a certain period of time. For example, an insurer may be willing to sell a policy to a person with asthma, but it can exclude any treatment or services related to asthma from the person's coverage. In a survey of adults who attempted to purchase policies in the private individual market in a three-year period, more than half (57 percent) found it very difficult or impossible to find a plan that they thought was affordable, and nearly half (47 percent) found it very difficult or impossible to find a plan that offered the coverage they needed.

Currently, five states have laws that require insurance companies in the individual market to accept all individuals who apply for coverage, regardless of their health status or other factors. However, even people in states that offer the greatest protections for those with pre-existing conditions aren't fully protected: If an individual in one of these states tries to buy a policy after being uninsured for at least 63 days, the insurer is still free to exclude coverage of his or her pre-existing conditions for a period of time, just like in every other state. In

Once health reform is fully implemented and strong consumer protections are put in place, all insurance companies will be required to sell coverage to all Americans and will not be allowed to deny coverage, charge people higher premiums based on their health status, or sell them policies that exclude coverage for certain health problems.

The Consequences of Coverage Denials

In our current system, a denial of coverage can lead to a broad range of adverse consequences. Many people who are denied coverage are forced to go without health insurance, which puts them at risk both physically and financially. Those who are uninsured are less likely to get the care that they need when they need it and are more likely to delay seeking care—often until a condition becomes so serious that treatment can no longer be put off. Quite often, the uninsured also suffer devastating financial consequences as a result of paying for this care. In addition, the fear of going without health coverage negatively affects productivity and the labor market because many Americans make decisions about which job to choose, or whether to stay in a job, based on whether the job provides health coverage—a phenomenon known as "job lock." By ensuring that everyone, regardless of health status, has an offer of coverage, health reform will help diminish these adverse consequences.

Poorer Health

The health consequences of going without coverage form a vicious circle. Those who do not have coverage often do not receive care when they need it. For example:

- Uninsured adults are six times more likely than those who are privately insured to go without needed care due to its cost (24 percent versus 4 percent).¹²
- Uninsured adults are seven times more likely than insured adults to have gone without preventive care in the last year (42 percent versus 6 percent).¹³
- Uninsured adults with chronic conditions are particularly at risk. Among uninsured adults with chronic conditions
 - nearly one-third (32 percent) went without needed medical care,
 - approximately 59 percent delayed care, and
 - three out of five (60 percent) did not fill a prescription due to cost.¹⁴

People who go without coverage are less likely to have a usual source of care outside of the emergency room, often go without screenings and preventive care, are more likely to delay or forgo necessary medical care, and end up sicker when they do get care. When uninsured adults put off seeing a doctor, illnesses that could have been prevented or treated easily often become much more serious, and people can end up with worse outcomes and have more troublesome diagnoses when they do seek care. The uninsured are therefore more likely to need intensive interventions. For example, it is important that individuals with diabetes monitor their blood sugar. Poor management of diabetes can lead to devastating consequences, such as kidney failure, blindness, and amputation, all of which can be prevented through good diabetes control.¹⁵

Of course, the worst consequence of being uninsured is premature death: Studies have shown that uninsured adults are at least 25 percent more likely to die prematurely than privately insured adults.¹⁶

■ Financial Burdens

When uninsured individuals do seek care, they often have to pay more for it. One reason for this is because uninsured individuals lack the buying power to negotiate discounts on medical services like insurance companies do for their customers. As a result, uninsured patients are often charged more than 2.5 times what insured patients are charged for the same hospital services.¹⁷

Another reason that people without insurance often pay more for care is because they delay getting the care they need. When people delay care, their health conditions often worsen and become more costly to treat. For example, uninsured women are substantially more likely than women with private insurance to be diagnosed with breast cancer in a later stage and to require more intensive treatment. Accordingly, their recommended treatment is likely to be more expensive, and they may suffer economically because of this. For example, more than two-thirds (68 percent) of people who were uninsured during cancer treatment say that the costs were a burden on their families.

When people cannot afford to pay for their medical care, they often find themselves with medical debt. In order to pay their debt, uninsured people may use up all of their savings, charge credit cards for bills that will take years to repay, or take out a loan or mortgage on their home. When those resources have been exhausted, people with medical debt may struggle to pay for basic necessities such as food, heat, clothing, and other basic necessities.²⁰

Medical debt is strongly linked to bankruptcy. In 2007, illness or medical bills were two key contributing factors to nearly two-thirds (62.1 percent) of all personal bankruptices filed.²¹ In addition, medical debt can lead to the loss of a home. One study found that nearly half of home foreclosures (49 percent) in four states were caused, at least in part, by financial issues stemming from a medical problem, such as illness or injury, medical bills that were beyond the person's ability to pay, or lost work because of their own medical problems or those of a family member.²²

Labor Market Inefficiency

In our current system, people with health conditions have a difficult time finding coverage in the individual market. Uncertainty about whether they'll be able to find affordable coverage leads many Americans to make decisions about which job to choose or whether to stay in a job based on whether the job provides health coverage. This phenomenon is known as "job lock." ²³

Job lock primarily affects individuals with health conditions who are considering leaving their current job for another job that does not offer health insurance. Workers who have health problems are less likely to leave a job that offers health coverage. One study found that chronically ill workers who rely on their employer for health coverage are about 40 percent less likely to leave their job than chronically ill workers who do not rely on their employer for coverage.²⁴ Another study found that workers with a history of health problems such as diabetes, cancer, or heart attack, and those who have substantial medical expenses, stay at their jobs significantly longer because of their job-based health coverage.²⁵

Job lock has a particularly strong effect on people who have family members with chronic illnesses. Research has shown, for example, that workers who rely on their employer to provide insurance for chronically ill family members stay in jobs that they might otherwise leave. One study found that women with job-based coverage who have a chronically ill family member that depends on that coverage are 65 percent less likely to leave their job than women with job-based coverage who have a chronically ill family member that does not depend on that employer coverage.²⁶

The fear of going without health coverage discourages individuals from leaving their existing jobs and starting new businesses of their own, especially if they have pre-existing conditions or if they have a family member with a health condition. Productivity is hurt when the new ideas, new products, and competitiveness that new businesses bring to the economy are lost. Health reform has the potential to significantly reduce the problem of job lock: Thanks to reform, individuals will no longer have to base their employment decisions on whether a job offers health coverage.

Conclusion

With the passage of health reform, all Americans, including those with pre-existing conditions, can be confident that they will be able to purchase insurance today and in the future. The newly passed legislation will have a profound effect on the millions of Americans who have pre-existing conditions. Because of health reform, insurance companies will no longer be allowed to deny people coverage based on health status, and 57.2 million nonelderly Americans who have a diagnosed pre-existing condition will no longer be at risk of being denied coverage. Nor will they face higher premiums or policies that exclude the very benefits they need. These new protections mean that every person will have access to highquality, affordable coverage.

Endnotes

- ¹ Centers for Disease Control and Prevention, *Health, United States, 2009: With Special Feature on Medical Technology, Tables 76 and 80* (Hyattsville, MD: Centers for Disease Control and Prevention, 2010).
- ² Agency for Healthcare Research and Quality, *National Healthcare Disparities Report*, 2008 (Rockville, MD: Agency for Healthcare Research and Quality, March 2009).
- ³ Kaiser Family Foundation, *How Private Health Coverage Works: A Primer, 2008 Update* (Washington: Kaiser Family Foundation, April 2008).
- ⁴ Lisa Girion, "Health Insurers Deny Policies in Some Jobs; Common Medications Can Also Be Deemed Too Risky in California," *Los Angeles Times*, January 8, 2007, available online at http://articles.latimes.com/2007/jan/08/business/fi-reject8.
- ⁵ Ella Hushagen and Cheryl Fish-Parcham, *Failing Grades: State Consumer Protections in the Individual Health Insurance Market* (Washington: Families USA, June 2008).
- ⁶ Statehealthfacts.org, Kaiser Family Foundation, *Individual Market Rate Restrictions (Not Applicable to HIPAA Eligible Individuals), 2010*, available online at http://www.statehealthfacts.org/comparetable.jsp?ind=354&cat=7, accessed on March 30, 2010.
- ⁷ Statehealthfacts.org, Kaiser Family Foundation, *Individual Market Portability Rules (Not Applicable to HIPAA-Eligible Individuals), 2010*, available online at http://www.statehealthfacts.org/comparetable.jsp?ind=355&cat=7, accessed on March 30, 2010.
- ⁸ Kaiser Family Foundation, op. cit.
- ⁹ Michelle M. Doty, Sara R. Collins, Jennifer L. Nicholson, and Sheila D. Rustgi, *Failure to Protect: Why the Individual Insurance Market Is Not a Viable Option for Most U.S. Families* (New York: The Commonwealth Fund, July 2009).
- 10 Ella Hushagen and Cheryl Fish-Parcham, op. cit. The five states are Maine, Massachusetts, New Jersey, New York, and Vermont.
- ¹¹ Heath Insurance Portability and Accountability Act of 1996, Public Law 104-191 (29 U.S. Code, Section 1181); Statehealthfacts.org, Kaiser Family Foundation, *Individual Market Portability Rules (Not Applicable to HIPAA-Eligible Individuals), 2010*, op. cit.
- ¹² Kaiser Family Foundation, *The Uninsured: A Primer, Key Facts about Americans without Health Insurance* (Washington: Kaiser Family Foundation, October 2009).
- 13 Ibid.
- ¹⁴ Ha T. Tu and Genna R. Cohen, *Financial and Health Burdens of Chronic Conditions Grow* (Washington: Center for Studying Health System Change, April 2009).
- ¹⁵ Andrew P. Wilper, Steffie Woolhandler, Karen E. Lasser, Danny McCormick, David H. Bor, and David Himmelstein, "Hypertension, Diabetes, and Elevated Cholesterol among Insured and Uninsured U.S. Adults," *Health Affairs* 28, no. 6 (2009): w1,151-1,159.
- ¹⁶ Institute of Medicine, *Insuring America's Health* (Washington: National Academies Press, 2002); Institute of Medicine, *America's Uninsured Crisis: Consequences for Health and Health Care* (Washington: National Academies Press, 2009).
- ¹⁷ Gerard Anderson, "From 'Soak the Rich' to 'Soak the Poor': Recent Trends in Hospital Pricing," *Health Affairs* 26, no. 3 (May/June 2007): 780-789.
- ¹⁸ Cathy J. Bradley, David Neumark, Lisa M. Shickle, and Nicholas Farrell, "Differences in Breast Cancer Diagnosis and Treatment: Experiences of Insured and Uninsured Patients in a Safety Net Setting," *Inquiry* 45, no. 3 (Fall 2008): 323-339.
- ¹⁹ USA Today/Kaiser Family Foundation/Harvard School of Public Health, *National Survey of Households Affected by Cancer* (Washington: Kaiser Family Foundation, November 2006).
- ²⁰ Sara R. Collins, Jennifer L. Kriss, Michelle M. Doty, and Sheila D. Rustgi, *Losing Ground: How the Loss of Adequate Health Insurance Is Burdening Working Families: Findings from the Commonwealth Fund Biennial Health Insurance Surveys, 2001-2007* (New York: The Commonwealth Fund, August 2008); Kaiser Family Foundation, *Kaiser Health Tracking Poll: Public Opinion on Health Care Issues, February 2009* (Washington: Kaiser Family Foundation, February 2009).
- ²¹ David U. Himmelstein, Deborah Thorne, Elizabeth Warren, and Steffie Woolhandler, "Medical Bankruptcy in the United States, 2007: Results of a National Study," *The American Journal of Medicine* 122, no. 8 (June 2009): 741-746.
- ²² Christopher Tarver Robertson, Richard Egelhof, and Michael Hoke, "Get Sick, Get Out: The Medical Causes of Home Mortgage Foreclosures," *Health Matrix* 18 (2008): 65-105.
- ²³ Michelle Conlin, "Held Hostage by Health Care: Fear of Losing Coverage Keeps People at Jobs Where They're Not Their Most Productive," *Business Week*, January 29, 2007; Brigitte C. Madrian, "Employment-Based Health Insurance and Job Mobility: Is There Evidence of Job-Lock?" *The Quarterly Journal of Economics* 109, no. 1 (February 1994): 27-54.
- ²⁴ Kevin T. Stroupe, Eleanor D. Kinney, and Thomas J. J. Kniesner, "Chronic Illness and Health Insurance-Related Job Lock," *Journal of Policy Analysis and Management* 20, no. 3 (Summer 2001): 525-544.
- ²⁵ Inas Rashad and Eric Sarpong, *Employer-Provided Health Insurance and the Incidence of 'Job-Lock': Is There a Consensus?* (Atlanta: Department of Economics, Georgia Health Policy Center, May 2006).
- ²⁶ Kevin T. Stroupe, Eleanor D. Kinney, and Thomas J. J. Kniesner, op. cit.

Technical Appendix:

Estimating the Number of People with **Specific Health Conditions**

Prepared by

The Lewin Group

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Introduction

The health reform law prohibits insurers from denying coverage, charging higher premiums, or eliminating coverage for certain health conditions to individuals because they have health conditions. Families USA and The Lewin Group (Lewin) conducted analyses to determine the number of people who currently have a diagnosed health condition that could exclude them from purchasing health insurance in the individual market.

Coding Excludable Health Conditions

The first step in estimating the number of people who would potentially benefit from eliminating pre-existing condition exclusions was to determine what conditions people are commonly denied insurance for. Families USA and Lewin examined lists of conditions that are used to determine high-risk pool eligibility in 19 states. We selected the 69 conditions that were most commonly included in lists for determining high-risk pool eligibility across all the states. To be included in the analysis, each condition had to be on the eligibility lists for at least five states.

The Lewin Group assigned either a Clinical Classification code (CCS) or an International Statistical Classification of Diseases code (ICD-9) to each of the conditions. The CCS codes aggregate five-digit ICD-9 codes into broad, clinically homogeneous, mutually exclusive categories. However, CCS categories do not exist for all conditions. Therefore, for each of the conditions, the analysis team assigned the condition to its umbrella CCS code if it existed. We assigned 25 conditions a CCS code.

The remaining conditions were identified using ICD-9 codes. One limitation of this analysis is that the Medical Expenditures Panel Survey (MEPS) 2007, which was the primary data source for the study, contains only three-digit ICD-9 condition codes. These three-digit ICD-9 codes provide a broader definition of disease categories than their five-digit counterparts. Ideally, more specific five-digit ICD codes would have been used, if available, for this analysis. As they were not, however, we included people in the analysis based on the available three-digit ICD-9 codes. Accordingly, this analysis may capture a broader group of people for some conditions and could overestimate the number of people with an excludable health condition for these conditions.

There were 42 conditions that were assigned an ICD-9 code. Two of the conditions, open heart surgery and topectomy/lobotomy, were not assigned a code because the MEPS does not have a highly inclusive collection of procedure codes. This may result in an underestimate of the number of people with an excludable health condition in this analysis. In addition, no data

were available for five of the conditions that were included in our list of 69: aplastic anemia, ALS (Lou Gehrig's Disease), Friedrich's ataxia, silicosis, and tabes dorsalis. It is possible that, due to sample size, the MEPS did not have enough records to capture these people, or that these conditions tend to occur more often in people living in institutions, who are not included in the MEPS sample.

Determining People in the MEPS with an Excludable Condition

We used the MEPS 2007 Medical Conditions file for this analysis. This file contains all medical conditions reported by each survey respondent based on records of medical events throughout the year. We identified the number of individuals with each excludable condition. We found that approximately 22 percent of the weighted MEPS sample under the age of 65 had at least one of these conditions.

Table 1 lists the conditions used for the study, the number of states that used these conditions for their high-risk pool eligibility, the CCS or ICD-9 codes for these conditions, and the weighted number of people under age 65 with those conditions. If a person had multiple diagnosed conditions, then separate records are included in the count of the number of people who have each condition. For example, a person with diabetes and kidney failure is counted under both conditions in the "Number of People under Age 65 with Each Condition" column of Table 1. However, this individual is counted only once in the total number of people with pre-existing conditions.

One caveat of the MEPS data is that they included only information on people's health conditions that were either treated or diagnosed in 2007. Therefore, this analysis would miss people who have a history of a specific condition but were not treated in 2007. This could underestimate the number of people with excludable health conditions in the analysis.

Table 1: Conditions Used in the Study

Condition	Number of States	ICD-9 Codes	CCS Codes	Number of People under Age 65 with Condition	Prevalence Rate
CSS					
Alcohol/Drug Abuse/ Chemical Dependency	9	-	660, 661	1,452,059	0.6%
Aortic Aneurysm	5	-	115	96,030	<0.1%
Cancer (except skin)	5	-	11-22, 24-36, 41	3,992,851	1.5%
Cardiomyopathy/Primary Cardiomyopathy	13	-	97	306,533	0.1%
Chronic Obstructive Pulmonary Disease (COPD)	7	-	127	10,783,692	4.1%
Chronic Pancreatitis	5	-	152	264,736	0.1%
Congestive Heart Failure	6	-	108	594,832	0.2%
Cystic Fibrosis	17	-	56	128,687	<0.1%
Diabetes	12	-	49 ,50	13,13 <i>7</i> ,506	5.0%
Hepatitis Active/ Hepatitis Chronic	12	-	6	619,557	0.2%
HIV+	15	-	5	255,646	0.1%
Hodgkin's Disease	13	-	37	22,826	<0.1%
Kidney Failure/ Kidney Disease w/ Dialysis/ Renal Failure	18	-	157, 158	393,992	0.1%
Leukemia	16	-	39	203,166	0.1%
Lupus Erythematosus Disseminate/Lupus	15	-	210	600,826	0.2%
Malignant Tumor*	10	-			
Motor or Sensory Aphasia	6	-	654	697,235	0.3%
Multiple or Disseminated Sclerosis	19	-	80	426,942	0.2%
Myocardial Infarction	6	-	100	1,434,469	0.5%
Parkinson's Disease	14	-	79	166,429	0.1%
Peripheral Arteriosclerosis	5	-	114	237,580	0.1%
Psychotic Disorders (e.g. Schizophrenia; Schizoaffective Disorder; Bipolar)	14	-	659, 657	22,229,882	8.5%
Rheumatoid Arthritis	9	-	202	2,064,915	0.8%
Sickle Cell Anemia / Sickle Cell Disease	8	-	61	101,731	<0.1%
Stroke (CVA)	14	-	109	1,386,696	0.5%

Table 1: Conditions Used in the Study (continued)

Condition	Number Of States	ICD-9 Codes	CCS Codes	Number of People under Age 65 with Each Condition	Prevalence Rate
		ICD-9			
Acquired Immune Deficiency Syndrome (AIDS)	19	042, 043, 044, 279, 795, 795, V08	-	915,873	0.3%
Alzheimer's Disease	12	331	-	93,537	<0.1%
Angina Pectoris	9	413	-	950,675	0.4%
Anorexia Nervosa	7	307.1	-	479,941	0.2%
Aplastic Anemia**	7	284	-		
Arteriosclerosis Obliterans	5	440	-	84,375	<0.1%
Artificial Heart Valve/ Heart Valve Replacement	9	V43.3	-	97,166	<0.1%
Ascites	10	789.5	-	1,793,126	0.7%
Brain Tumor	5	191, 225	-	92,783	<0.1%
Cancer, Metastatic	12	196.0-199.1	-	459,850	0.2%
Cerebral Palsy/ Palsy	12	343	-	238,850	0.1%
Cirrhosis of the Liver	17	571	-	274,693	0.1%
Coronary Artery Disease	5	410-414, 429.2	_	6,541,349	2.5%
Coronary Insufficiency*	10	411.1	-		
Coronary Occlusion*	9	411.81	-		
Crohn's Disease	14	555	-	268,677	0.1%
Dermatomyositis	9	710.3	-	600,826	0.2%
Emphysema/ Pulmonary Emphysema	8	492	-	961,883	0.4%
Friedreichs's Disease/ Ataxia**	11	334	-		
Hemophilia	1 <i>7</i>	286	-	<i>77</i> ,912	<0.1%
Huntington's Chorea/ Disease	15	3334	-	910,259	0.3%
Hydrocephalus	13	742.2-742.4, 331.3-331.7	-	93,537	<0.1%
Intermittent Claudication	7	440.21	-	84,375	<0.1%
Lead Poisoning with Cerebral Involvement	8	984.9	-	58,896	<0.1%
Lou Gehrig's Disease/ Amyotrophic Lateral Sclerosis/ALS**	13	335.2	-		
Major Organ Transplant	9	V42	-	17,148	<0.1%
Muscular Atrophy or Dystrophy	19	359	-	105,304	<0.1%
Myasthenia Gravis	16	358, 775.2	-	15,265	<0.1%
Myotonia	8	359.2	-	105,304	<0.1%
Obesity	5	BMI >= 35	-	19,707,701	7.5%
Open Heart Surgery/ Heart Bypass Surgery***	9	-	-	n/a	n/a
Paraplegia or Quadriplegia	17	344	-	106,074	<0.1%
				,	

Table 1: Conditions Used in the Study (continued)

Condition	Number Of States	ICD-9 Codes	CCS Codes	Number of People under Age 65 with Each Condition	Prevalence Rate
Polyarteritis (Periarteritis Nodosa)	9	446	-	39,578	<0.1%
Polycystic Kidney	9	<i>7</i> 53.1	-	156,213	0.1%
Postero-Lateral Sclerosis	8	336	-	153,404	0.1%
Silicosis**	8	502	-		
Splenic Anemia/ True Banti's Syndrome/ Banti's Disease	9	289.4-289.5, 759.0	-	551,592	0.2%
Still's Disease	8	714.2, 714.3	-	2,033,324	0.8%
Syringomyelia (Spina Bifida or Myelomeningocele)	15	336, 742	-	153,404	0.1%
Tabes Dorsalis (locomotor ataxia)**	8	94	-		
Thalassemia (Cooley's or Mediterranean Anemia)	6	282.4	-	101,731	<0.1%
Topectomy and Lobotomy***	8	Procedure	-	n/a	n/a
Ulcerative Colitis	10	556	-	121,748	<0.1%
Wilson's Disease	13	275.1	-	151,173	0.1%

Note: Includes all non-institutionalized people under age 65.

Source: Lewin Group analysis of 2007 MEPS data.

^{*} Indicates conditions that are already included in other condition categories. Malignant tumor is included in cancer. Coronary insufficiency and coronary occlusion are included in coronary artery disease.

^{**} No records were found for the following conditions: aplastic anemia, Friedrich's ataxia, ALS, silicosis, and tabes dorsalis. It is possible that, due to sample size, MEPS did not have enough records to capture these people, or that these conditions tend to occur more often in people living in an institution who are not included in the MEPS sample.

^{***} MEPS does not have a highly inclusive or detailed collection of procedure codes, so the analysis could not produce any information on the number of people with open heart surgery or topectomy/lobotomy.

Generating State-Level Estimates

The MEPS data do not provide state identifiers, so we could not use these data to generate state-level estimates of the number of people with at least one of these conditions. Therefore, we developed a probabilistic predictive model to determine the probability of having at least one of the conditions based on a person's age, gender, race, employment status, income as a percent of poverty, health insurance status, reported health status, and Census region.

We used the MEPS 2007 Full Year Consolidated File to determine insurance status and demographic characteristics for the sample. We selected only people under age 65 who did not report having Medicare coverage. In addition, it is important to note that the MEPS does not include people who live in institutions. Individuals were assigned insurance statuses based on the number of months (out of 12 months) that they spent without insurance, with Medicaid, with private non-group insurance, or with private employer-based insurance.

Using the MEPS demographic information, the analysis team created categories for the following independent variables: age, race/ ethnicity, employment status, selfreported health status, income level, sex, and region. The dependent variable was whether the person had an excludable health condition in that year. Table 2 shows the parameters from the model.

Table 2: Model Parameter

Parameter	Estimate
Age Group	
0-17 25-34 35-44 45-54 55-64	-0.2650* 0.2030* 0.3108* 0.5014* 0.6970*
Female	0.0969*
Black	-0.0744*
Race/Ethnicity	
American Indian/Alaskan Native Asian or Hawaiian/Pacific Islander Hispanic	0.00131* -0.5824* -0.2543*
Health Status (self-reported as excellent, very good, good, fair, or poor)	0.3714*
Family Employment Status	
Not Employed Any Time During Year Not Employed - Child	0.1928* -0.2207*
Insurance Status	
Private Non-Group Medicaid Uninsured	-0.1700* -0.1705* 0.1870*
Income as Percent of Federal Poverty Level	
125-200 200-400 >400	0.00945* -0.0228* -0.0879*
Region	
Northeast Midwest West	-0.0610* 0.0292* -0.0115*

^{*} Significant with 95% confidence

The MEPS model was then applied to the Current Population Survey (CPS). In order to produce reliable estimates at the state level, we pooled the three most recent years of CPS data for 2007 through 2009 to increase the sample size (N=544,744). The model assigned each person in the CPS a probability of having at least one of the conditions based on his or her age, race/ethnicity, employment status, self-reported health status, income level, and gender.

Lewin compared CPS national estimated results with actual MEPS data by demographic and insurance breakdowns for people to check for consistency. The CPS and MEPS results were comparable, so we created state-level tables. Separate tables were created for age, income level, sex, family employment status, and self-reported health status. Each table presents the number of people under age 65 without Medicare coverage by insurance status, the estimated number with an excludable health condition, and the percent with an excludable condition for each state and the District of Columbia. We highlighted each cell where we felt the sample size was insufficient to produce reliable estimates (fewer than 30 cases).

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