

A Report from The Robert Wood Johnson Foundation  
National Strategic Indicator Surveys

# A Portrait of the Chronically Ill in America, 2001



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ROBERT WOOD  
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**FACCT**  
FOUNDATION FOR ACCOUNTABILITY

### ***Principal Investigators***

FACCT—The Foundation for Accountability

Christina Bethell, PhD

David Lansky, PhD

The Robert Wood Johnson Foundation (RWJF)

John Fiorillo, MA

### ***The Robert Wood Johnson Foundation (RWJF)***

Project Director: James Knickman, PhD

Project Officer: John Fiorillo, MA

### ***Data Collection Partners***

E-valuations, Inc., Seattle, WA

Common Knowledge, Inc., Dallas, TX

### ***FACCT Editorial and Production Staff***

Ravi Singh, MA

Elizabeth Whitworth, MPH

Louise Dunn, MPA

Willow Cordain, BS

### ***FACCT Data Management and Analysis Staff***

Michael Hendryx, PhD

Emily Huang, PhD

Krista Brockwood, MS

Kris Gowen, PhD

### ***Book and Chart Design***

Eagle Design & Management, Bethesda, MD

**FACCT—The Foundation for Accountability**

1200 NW Naito Parkway, Suite 470

Portland, OR 97209

[www.facct.org](http://www.facct.org)

**The Robert Wood Johnson Foundation**

Route 1 and College Road East

P.O. Box 2316

Princeton, NJ 08543-2316

[www.rwjf.org](http://www.rwjf.org)

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# Acknowledgements

This Portrait of Chronic Disease in America is one of three data portraits produced in 2002 by The Robert Wood Johnson Foundation as part of its National Strategic Indicators Project. Other volumes in the series address the experience of caregivers and teens in today's health system.

Many different people and organizations have been involved in the framing and construction of this Portrait of Chronic Disease in America. Jim Knickman and John Fiorillo at the Foundation provided the initial conceptualization as well as continuing oversight to the project. Christina Bethell and David Lansky at FACCT executed the design, administration, analysis, and reporting of the surveys. Sandra Bauman and Paul Egli of Wirthlin Research provided expert advice on weighting issues.

The surveys themselves reflect the contributions of many investigators over the past decade. Health services researchers, clinical scholars, and survey methodologists have developed superb tools for measuring the health and health care quality experiences of people with chronic illness. We particularly acknowledge those individuals and organizations that have been key sources of survey items and measures. These include items and measures developed by the California Healthcare Foundation, the Centers for Disease Control and Prevention, the Diabetes Patient Outcomes Study (Greenfield, et al.), Harris Interactive, the Outcomes Measures for Health Education project at Stanford University (Lorig, et al.), and the Outcomes Management System coordinated by Johns Hopkins University (Steinwachs, et al). We also offer special appreciation and heartfelt thanks to the individuals who participated in the survey.

# Introduction: How Americans Experience Their Health And The Health Care System

## INTRODUCTION

Almost one-half of all Americans report having a chronic illness – and they account for 75% of our national spending on health care. Almost one in five Americans have hypertension, one in ten report clinical depression, and one in twelve have asthma. On average, people with chronic illness cost 3.5 times as much to serve as all others.

The importance of this population and its needs has led to a surge in serious research and experimentation. Information abounds about the prevalence, cost, and emerging care models appropriate to these patients – but little coherent summary information is available on how well Americans are living with chronic illness, how well they are able to care for themselves, and how well our health system cares for them.

While it's become more evident that patients and their caregivers are vital partners in managing chronic illness, we've also begun to realize that only by listening to patients and caregivers can we evaluate whether our investments in health care are achieving their objectives. Are patients achieving maximum achievable levels of routine functioning and quality of life? Are those with chronic illness able to manage their problems, comply with recommended therapies, minimize symptom burden, and avoid serious complications? Are our health professionals and health care organizations delivering state-of-the-art care to their patients? Are there barriers to care, or systematic and inappropriate variations in care that can be corrected?

This report explores these questions by applying new techniques in web-based data collection. The Robert Wood Johnson Foundation, in collaboration with the Foundation for Accountability, has conducted a series of on-line surveys of chronic disease sufferers to learn more about their lives and their care. The project makes use of commonly used, scientifically validated survey instruments and wide-net samples drawn from Internet users to make estimates of health care attitudes and behaviors. The project is an early step in a long-term project of refining emerging technologies to provide policymakers with rapidly available, relevant information to shape programs.

We focus on the patient's own perspective on his or her care in order to better understand both the strengths of people affected by chronic illness and opportunities to make the health care system more responsive to their needs.

This study included surveys with over 6,000 people suffering from one of six conditions: arthritis, asthma, coronary artery disease, diabetes, depression, and hypertension. Most people were asked a common core set of questions, and each group was also asked questions specific to the recommended medical practices for their particular diagnosis.

In all, we computed over 150 measures on over 6,000 chronic disease sufferers in a one-month data collection period (May 2001). The data can be accessed and analyzed in many ways, of course, including detailed tables and roll-up indices. In addition, wherever possible, we have sought to benchmark the data from our survey against standardized data for the general population derived from the well-established BRFSS surveys. Footnotes in the charts or text identify instances where BRFSS data are used.

In this overview, we highlight a few themes that appear to be intrinsic to the experience of all those suffering from chronic illness in America.

We ask and try to answer four questions in this report:

1. What is the impact of chronic illness on the overall health, behavior, and quality of life of those affected?
2. Can people with chronic illness get access to needed medical care and related services?
3. Is the U.S. health system providing the appropriate, recommended services to people with chronic illness?
4. Are people with chronic illness working effectively as partners with health professionals in managing their illness?

These surveys tell a very mixed story about living with chronic illness in America. Many Americans report excellent access to the health system, and satisfying relationships with their doctors. Many people – between one-half and three-quarters – seem to get most of the services recommended by consensus practice guidelines.

But the story here is mixed in two ways.

First, the frequently documented gaps in economic and cultural access to the health system are *magnified* for the chronically ill. The uninsured and underinsured report poorer quality of life, fewer visits to doctors, less adequate knowledge of how to care for their illness, poorer relationships with their doctors, and less complete benefit from modern standards of care. Similarly, African-Americans, Hispanics, and women often report receiving less good care.

Secondly, about one-third of the chronically ill in America simply are not receiving the information and services needed to manage their illness successfully. We find remarkably high rates of dangerous health behaviors among people with distinctively high risks for complications



of their illness. Almost two-thirds of diabetics do not exercise regularly, and 38% have never had a doctor observe them monitoring their blood sugar; 26% of coronary disease sufferers surveyed still smoke – and only half of them have had a doctor advise them to quit; 40% of those with hypertension say they have not been advised to limit salt intake or control their weight.

And while the great majority of patients express confidence in their doctors, only about one-half of those we surveyed feel fully involved with their doctor in making decisions about their care or can translate that relationship into a confident sense of how to manage their illness. Among diabetes sufferers, for example, 42% reported that they had never been advised – or still were confused – about how to manage their illness.

Americans with chronic illness tell a positive story, but one with many gaps that remain to be filled. People are functioning, learning, and managing. They are using our health system, seeing their doctors, getting many of the right tests and treatments, and managing to live their lives with only modest limitations. But our system is falling short. Too many Americans who could be living more completely, more productively and with less suffering are instead just coping.



# Living With A Chronic Illness

## OVERVIEW

People with chronic illnesses are about twice as likely to “have a bad day” as other Americans. They report twice as many days when they could not function normally, and are twice as likely to say they are in poor or fair health.

The burden of chronic illness is primarily carried in terms of physical health; people with chronic illnesses generally report the same levels of mental health and functioning as the general population.

Researchers and policymakers have long understood that chronic illness is more prevalent among people with low incomes and among disadvantaged populations. Not only are these illnesses more common, but their impacts are more severe among the unemployed, uninsured and less educated. People with chronic illness and less than high school education, for example, are three times more likely to say they are in poor health than people with the same illness who hold a college degree.

The impact of chronic illness on overall health also varies, of course, by condition. Of the diagnoses we studied, people with heart disease and arthritis are most likely to report a serious impact on their overall health and functioning.

Americans with chronic illness are no more or less likely than others to choose healthy behaviors and lifestyles. And physicians – while seeing these patients far more often than others – often fail to communicate the importance of healthy living and the mechanics of disease management skills to their patients. While the consequences of poor exercise, smoking, and alcohol misuse are far greater for people with depression, diabetes, and heart disease than for the general population, physicians do not seem to be aggressive in offering their patients counseling on changing these risky behaviors.

### *People with chronic illness:*

- ❖ Are twice as likely to suffer bad health days as other Americans
- ❖ Typically have four more days every month when they cannot function normally
- ❖ Report comparable mental and emotional health as other people
- ❖ Experience additional burden if they have low income, less education, suffer from heart disease or diabetes

## 1.1 WHAT IS THE OVERALL HEALTH STATUS OF PEOPLE LIVING WITH A CHRONIC ILLNESS?

More than half of all Americans (56%) describe their overall health as excellent or very good<sup>1</sup>. But only one-fourth of those with chronic illness report such good overall health – with one-third saying that their health status is fair or poor, compared to 13% of the general population.

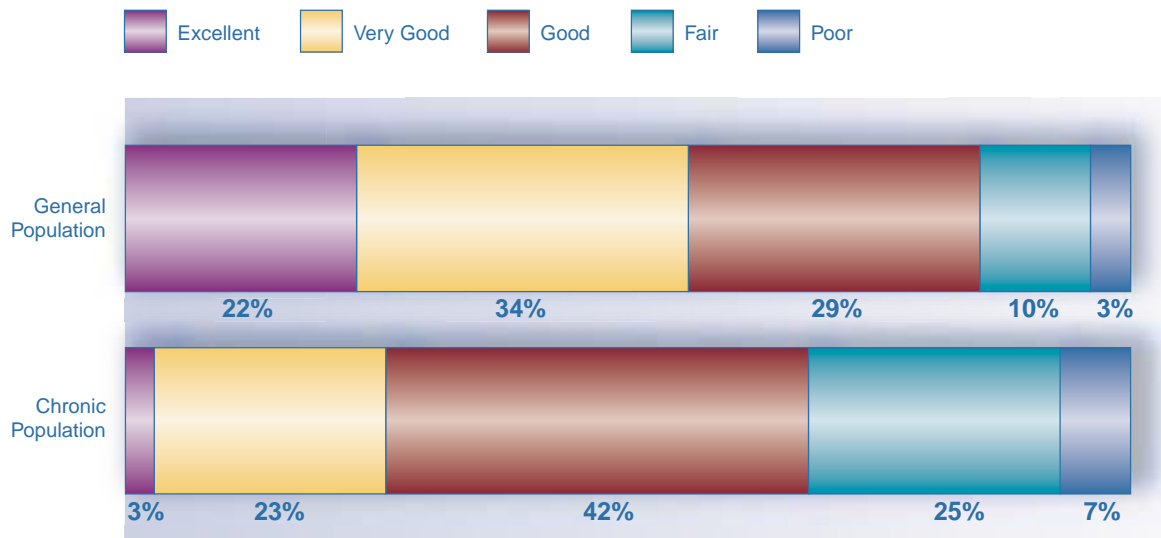
This relatively poorer perceived quality of life for those with chronic illness is further diminished by other characteristics: women, non-whites, those aged 45 to 64, those who are not employed and the uninsured are all more likely to report poor health status than others.

Similarly, the lower a respondent's income and/or the lower their education level, the more likely they are to report poor health status.

Among the six chronic populations surveyed, those with diabetes and cardiovascular disease (CAD) reported the lowest average health status. Forty-two percent of those who suffer from coronary artery disease and 40% of those afflicted by diabetes reported either a fair or poor health status, as compared to only 13% of the general population. In comparison, those suffering from hypertension are the least likely to report poor health (22%), while approximately one-third of those suffering from arthritis (34%), depression (32%) and asthma (31%) report a similar health status.

### Chart 1: Health Status

Self-reported health status of general adult and chronic adult populations



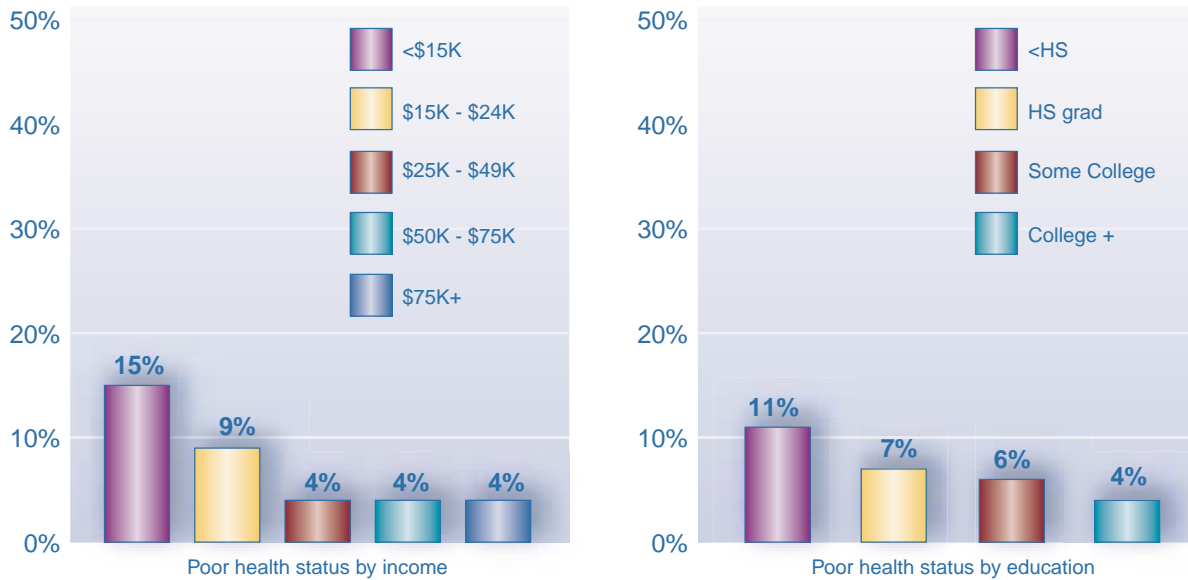
General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

General Population numbers do not add to 100% due to rounding.

<sup>1</sup> BRFSS: For complete citation see footnote on Chart 1.

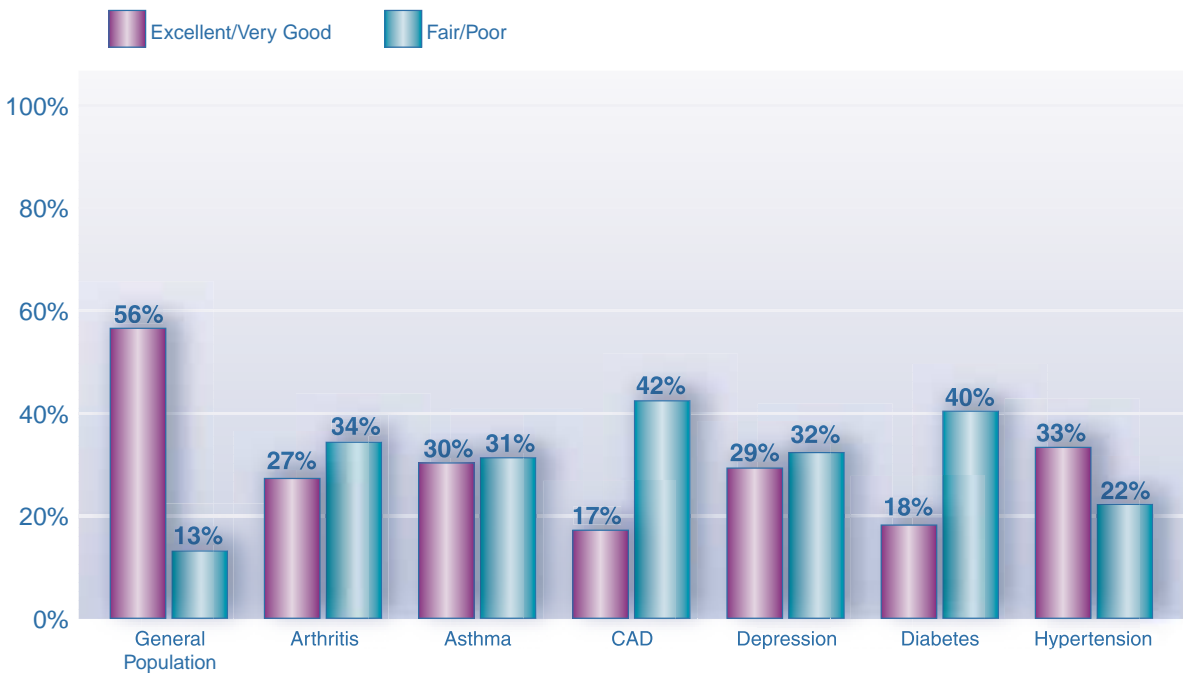
## Chart 2: Poor Health Status

Self-reported poor health status—by income and education



General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

## Chart 3: Health Status by Chronic Illness



General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

## 1.2 TO WHAT EXTENT DOES A CHRONIC ILLNESS AFFECT ONE'S DAILY FUNCTIONING?

The Centers for Disease Control have established a standardized approach to evaluating the impact of ill health on daily functioning; this approach was adopted for this survey as well. The Behavioral Risk Factor Surveillance Survey – administered to more than 1 million Americans since 1993 – asks:

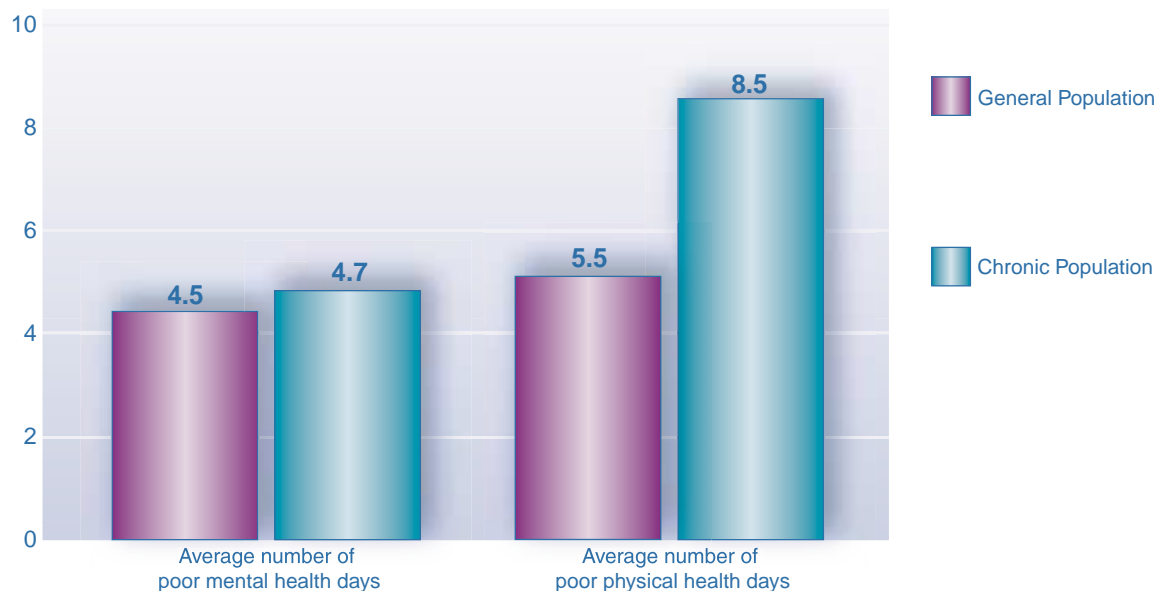
Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

On average, respondents who suffer chronic illness report a greater number of poor physical and mental health days than the general adult population. While the average number of poor mental health days is only slightly higher among those who suffer from a chronic condition, people with a chronic condition report three additional days of poor physical health in the past 30 days.

### Chart 4: Poor Physical and Mental Health Days

Average number of days reported by chronic and general populations



General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

### **Poor Physical Health Days**

As many as 68% of those who suffer from a chronic condition have had at least one poor physical health day in the past 30 days, compared to 55% of the general population.<sup>2</sup>

Over one-third appear to suffer serious limitations in their ability to work and participate in routine activities: 36% of chronic condition sufferers had seven or more poor physical health days in the past 30, compared to 12% of the general population.

As can be seen in Chart 6 on the next page, a significant proportion of those surveyed that have a chronic condition are in extremely poor physical health. Most respondents who have a chronic illness tend to fall on one end or the other of the spectrum—typically, people with chronic illnesses either suffer from 4 or fewer days of poor physical health, or suffer from many (20 or more bad physical days in a month); fewer suffer between 5 and 19 days a month. Overall, 14% report having a bad physical day every day of the past 30 days. In contrast, only half as many among the general population report having had a bad physical health day every day (6%).

Those with annual incomes under \$25,000, those who have not studied beyond high school, and those who are either unemployed or do not have health insurance, are more likely than others to have at least one poor physical health day.

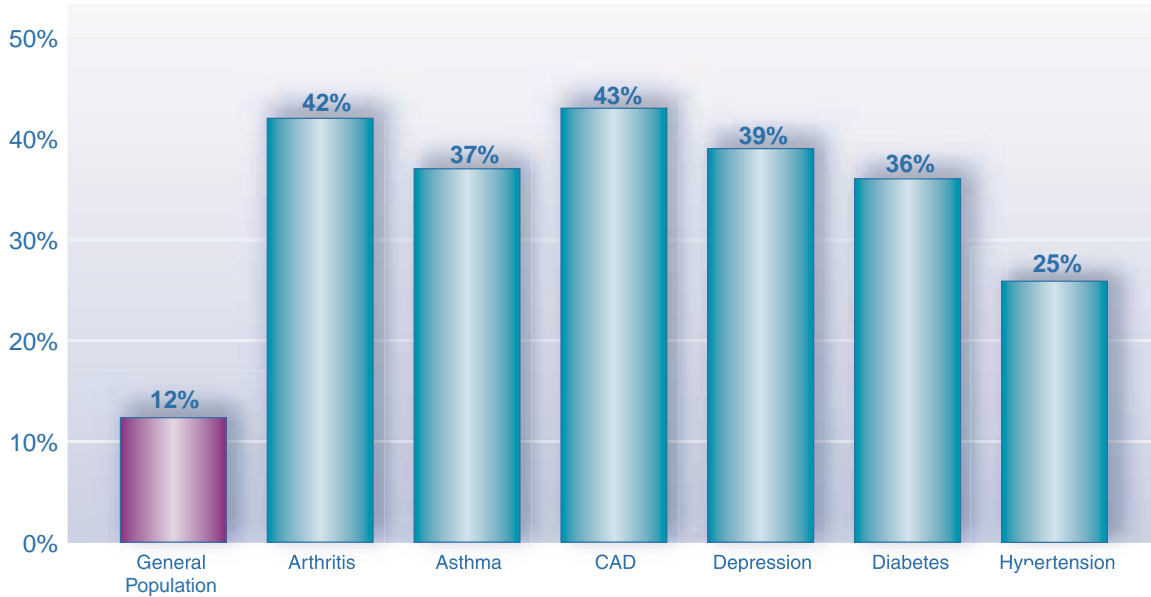
Among the six chronic populations surveyed, those who suffer from coronary artery disease (43%), arthritis (42%) and depression (39%) are most likely to report serious limitations (having seven or more poor physical health days in the past 30 days), and are three times as likely as the general population (12%) to say so. Whites and those over age 45 are most likely to report such severe limitations.

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<sup>2</sup> BRFSS: For complete citation see footnote on Chart 1, pg. 6.

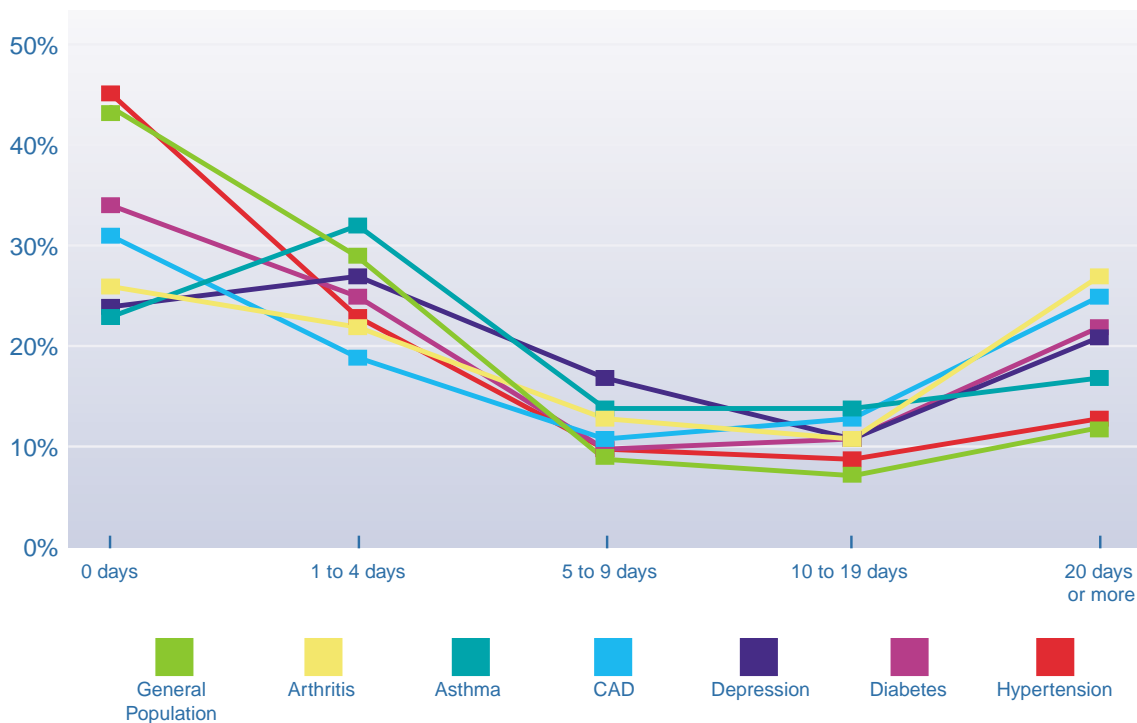
### Chart 5: Population in Poor Physical Health

Percent who reported at least 7 poor physical days in the past 30



General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

### Chart 6: Proportion of Bad Health Days





### Poor Mental Health Days

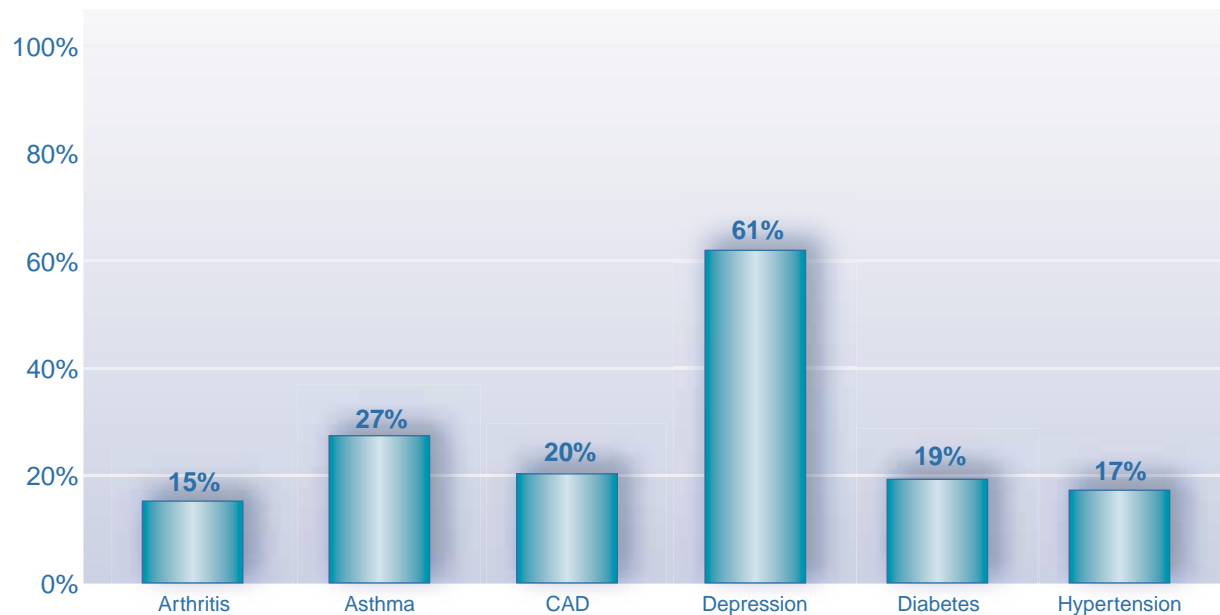
People with a chronic illness are slightly less likely to report having a bad mental health day in the past month than are members of the general population (45% vs. 49% respectively).<sup>3</sup>

The likelihood of suffering a bad mental health day increases inversely with age (73% of 18 to 24 years old suffered a bad mental health day, compared to 57% of those 25 to 44, 46% of those aged 45 to 64 and 26% of those over age 65). Respondents with low household incomes, those who have not graduated from high school, and the single and uninsured are all more likely to report at least one bad mental health day a month.

Among the conditions studied here, depression sufferers naturally report the most severe limitations due to mental health, with 86% reporting at least one poor mental health day in the last month, with a mean of 12.2 bad days. Three-fifths of depression sufferers had seven or more poor mental health days in the past 30 days, a proportion almost three times higher than any other surveyed population.

### Chart 7: Population in Poor Mental Health

Percent who reported at least 7 poor mental health days in the past 30



<sup>3</sup> BRFSS: For complete citation see footnote on Chart 1, pg. 6.

## 1.3 HOW WELL DO PEOPLE COPE WITH AND MANAGE THEIR CHRONIC ILLNESSES?

People who suffer from chronic illnesses continue to engage in risky health behaviors at rates comparable to the general population, despite the higher health risks posed to them.

Across the board, the chronic illness population is slightly less likely than the general adult population to smoke or drink at risky levels. They are, however, also somewhat less likely to exercise.

### ***Asthma***

The asthma sufferers we surveyed represented the national distribution<sup>4</sup> of asthma severity. One in ten classified their asthma as severe, another one-third reported moderate asthma, while the rest described their asthma as mild.

Practice guidelines generally recommend infrequent use of medications and formal self-monitoring for people with mild illness but encourage moderate and severe sufferers to use a peak flow meter, have an inhaler, and be observed by their doctor in its correct use.

Virtually all (or 99.5%) of the moderate and severe sufferers<sup>5</sup> surveyed had been prescribed an inhaler by their physician and 95% of all moderate and severe sufferers use them. Among those who use inhalers, two-thirds (67%) are completely dependent on them and say they use them everyday. About one-third (29%) say they use their inhaler less often than advised.

In addition, one-third (32%) say they have suffered an asthma attack. Of those who have had an attack, 42% say they have had an attack that was serious enough that they could have died. No demographic characteristics were associated the likelihood of an attack.

The majority of asthma sufferers (57%) do not regularly exercise, 30% smoke regularly and 12% are classified as at-risk drinkers.

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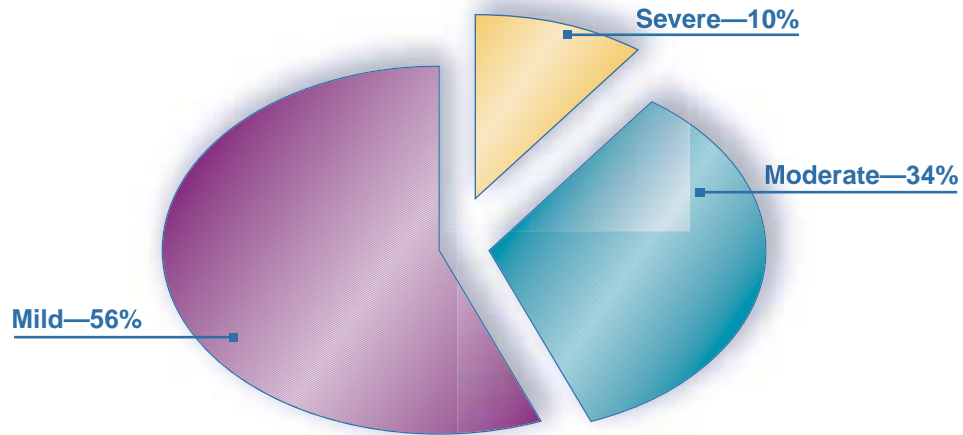
<sup>4</sup> Steinwachs, D. M., Wu, A., Skinner, E. A., Campbell, D. (1995). Asthma patient outcomes study: Baseline survey summary report. Distributed by The Health Outcomes Institute, Bloomington, MN.

<sup>5</sup> A person is deemed to be suffering from severe or moderate asthma if they either:

- Had an attack where they could have died, or
- Had a tube put down their throat to help with breathing during an attack, or
- Take inhaled steroids every day or less often than advised.

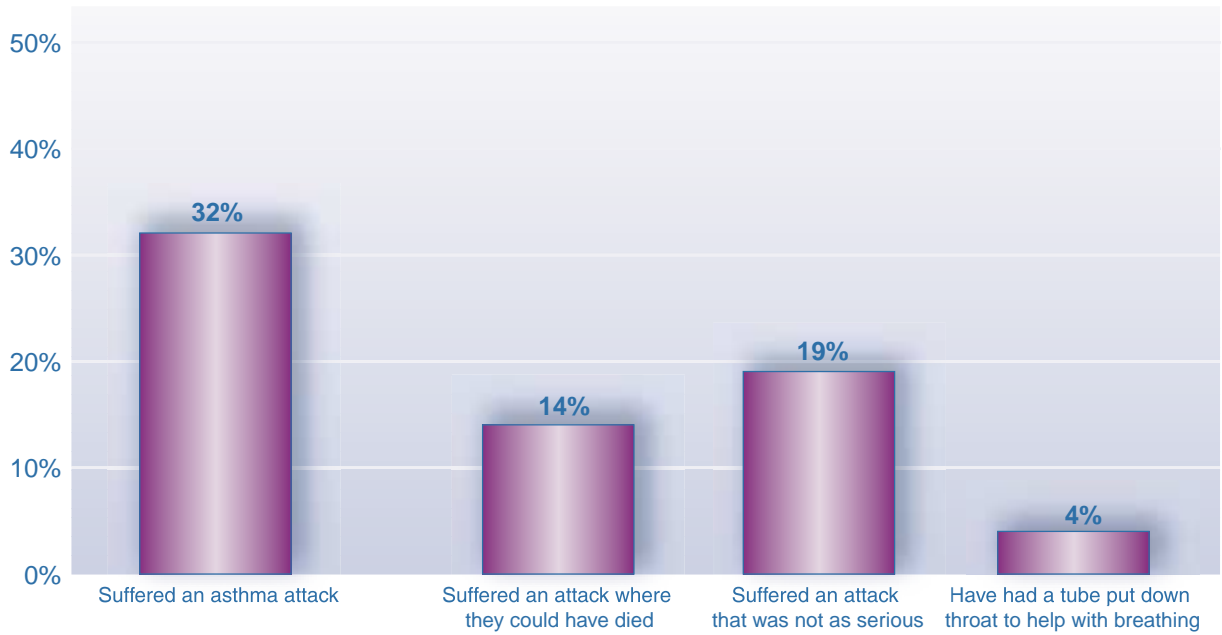
### Chart 8a: Asthma Severity

Percent of survey respondents who describe their asthma as...



### Chart 8b: Prevalence and Severity of Asthma Attacks

Percent of moderate or severe asthma sufferers who...



## Diabetes

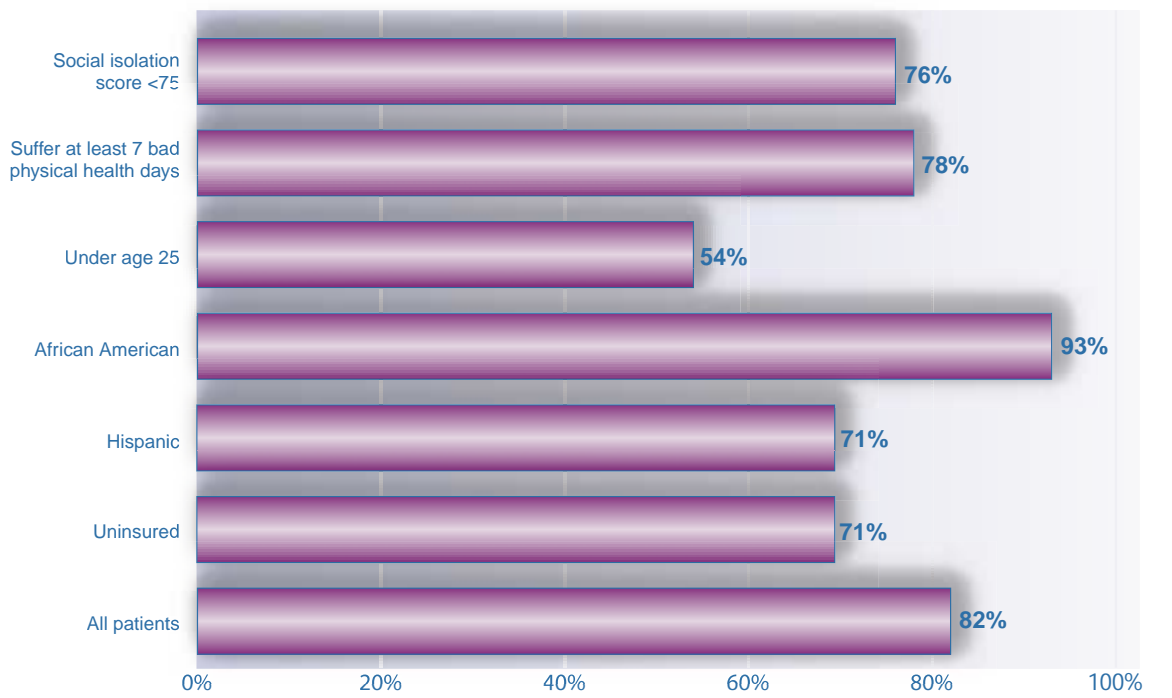
The vast majority of diabetes sufferers (82%) feel very or somewhat confident about managing their illness (operationalized to include three factors: keeping blood sugar under control, managing diabetes away from home and testing blood sugar). However, the minority of patients who report low confidence in self-management are disproportionately younger – aged 18-24 – and lacking health insurance.

The diabetes patients surveyed represented a cross-section of severity. About one in five depend on insulin injections to manage their illness (19%), three-fifths rely on oral medications, and the remainder control their diabetes through diet and exercise (21%). Interestingly, only one-third of those who say they primarily manage their diabetes through diet and exercise actually do exercise on a regular basis; in fact, their exercise levels are only slightly higher than those of the general population. Yet patients in this subset of diabetics are also the most likely to be very confident of their ability to manage their diabetes (49%).

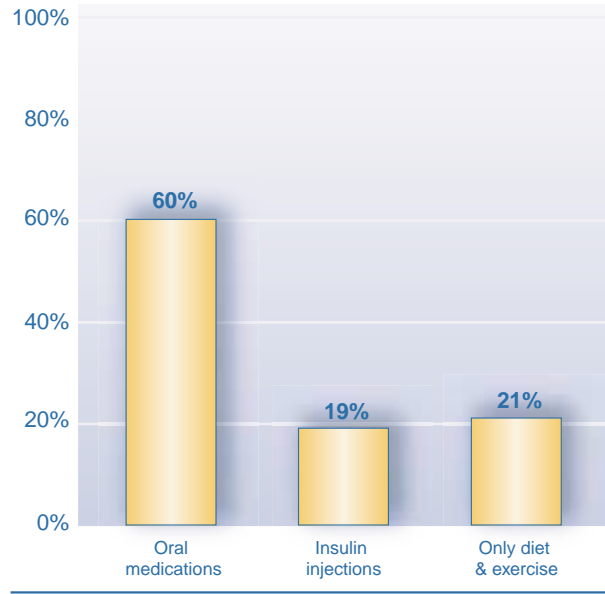
While most diabetics surveyed said they feel confident about managing their diabetes, their reports of specific health behaviors and self-care knowledge point to less-than-optimal care. Three-fifths of diabetes sufferers indicate they do not exercise (61%), 20% admit smoking regularly, and 7% are at-risk drinkers.

**Chart 9a: Confidence in Managing Diabetes**

Percent who are very/somewhat confident of own ability to manage diabetes

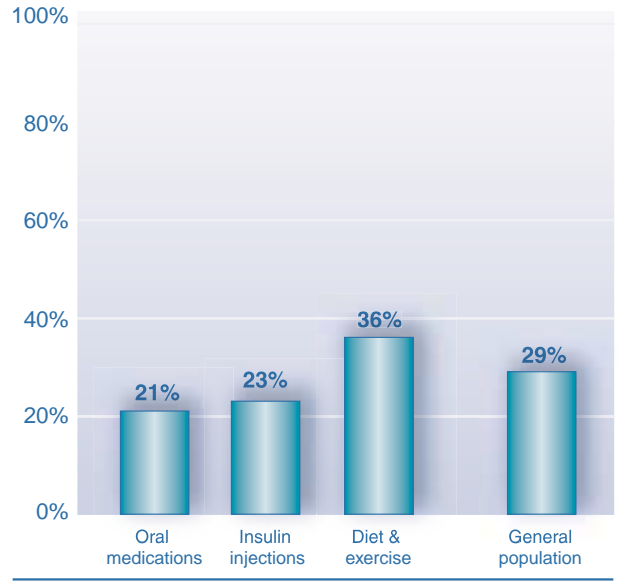


**Chart 9b: Primary Diabetes Management Technique**



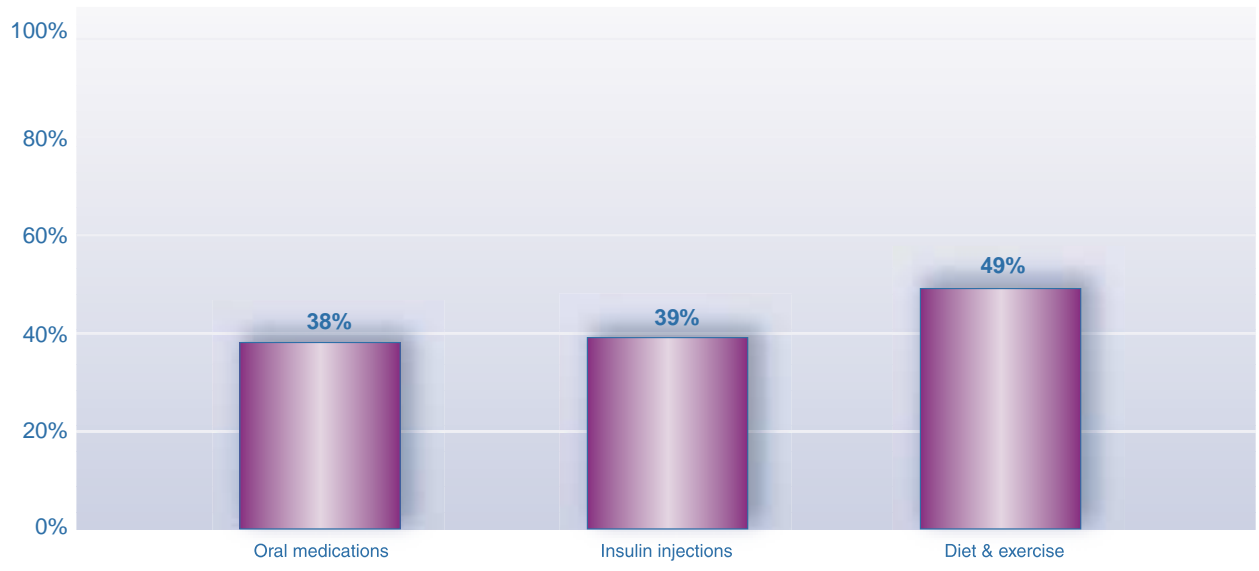
**Chart 9c: Physical Activity Levels**

Percent who regularly exercise among those who manage their diabetes by...



**Chart 9d: Overall Confidence and Management Technique**

Percent who are very confident of own ability to manage diabetes among those who manage their condition by...



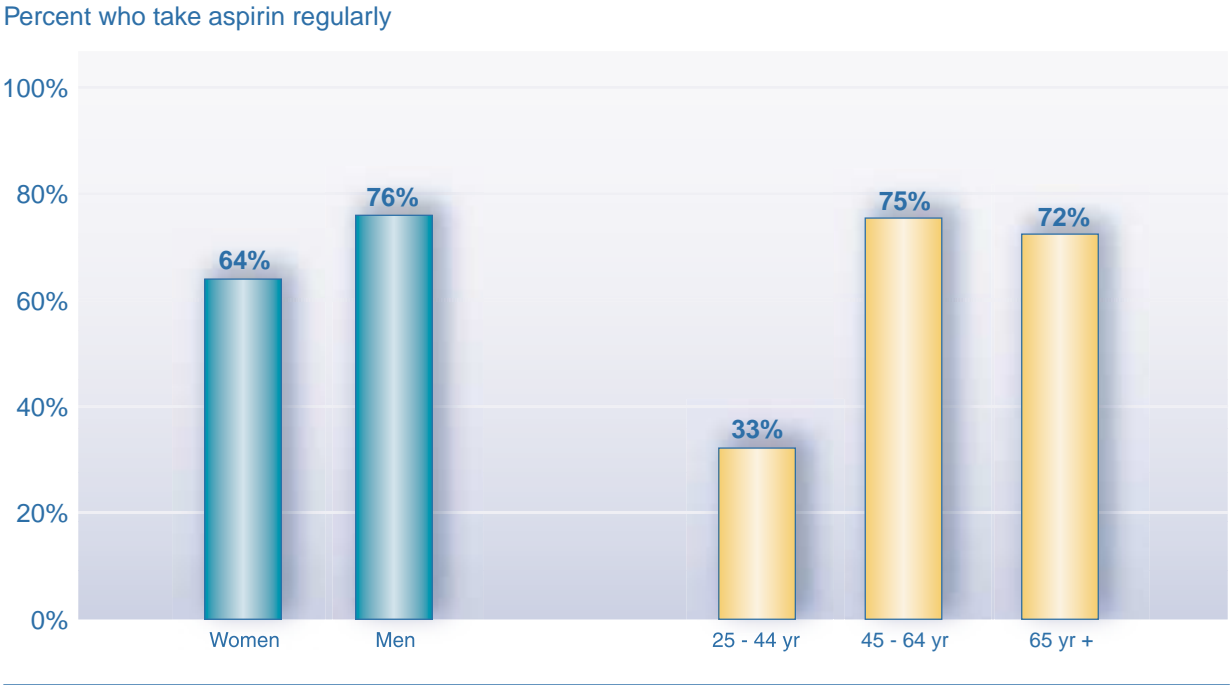
**Coronary Artery Disease (CAD)**

Many CAD sufferers are not adopting behaviors – both lifestyle and medical – that could help them reduce the risks of continued progression of their illness. Everyone in the surveyed population is a candidate for aspirin therapy, for example. While 71% of all CAD sufferers take aspirin regularly, African-Americans, women and those younger than 45 years old were all significantly less likely to do so.

A subpopulation of the CAD group – those with a history of heart attack (acute myocardial infarction) – are expected to be prescribed and take beta blocker medication to prevent recurrent attacks. In the survey group of post-heart attack patients, half (52%) say they take beta-blockers. Interestingly, those who come from households with lower incomes (i.e., households with annual incomes of \$25,000 or less) are more likely than others to take them.

CAD sufferers did not report high levels of attention to the specific health behaviors known to be associated with high risks of recurrent heart problems. More than half do not exercise regularly (58%), one-quarter smoke (26%) and 11% report drinking patterns that qualify as high-risk for alcohol misuse. Respondents from lower income households exercise less frequently, while smoking rates among 45 to 64 year olds (39%) are especially high.

**Chart 10a: CAD Sufferers' Use of Aspirin**



### Chart 10b: Smoking and Alcohol Consumption Patterns

Percent of CAD sufferers who smoke or are at-risk drinkers by age



### Chart 10c: Physical Activity Among CAD Sufferers

Exercise levels among CAD sufferers by income



## ***Depression***

As many as one-third of those who suffer from depression are currently not receiving any treatment, while 11% have never received treatment. Non-whites are the least likely to have received treatment from a counselor, therapist or doctor for their depression (88% of whites have received treatment, compared to 77% of African-Americans and 64% of Hispanics).

Many individuals who suffer from depression also exhibit risky behaviors that are detrimental to their overall health and well-being. Consider for example, that as many as 42% are smokers and close to one-fifth of this population are at-risk alcohol drinkers (17%). In addition, close to three-quarters do not undertake physical exercise on a regular basis (72%); in fact, 55% indicate they have not been physically active in the past six months.

About one-quarter (23%) of those who are on prescribed medication are not taking it. Those between the ages of 18 to 24 (36%) and those who have no insurance (37%) are the most likely to fail to take medication. In addition, single people (31%), Hispanics (53%) and African-Americans (32%) report lower rates of taking prescribed medication.

Among those surveyed, 65% are currently in treatment, with younger people (54%) and the uninsured (20%) with the lowest rates of treatment participation.

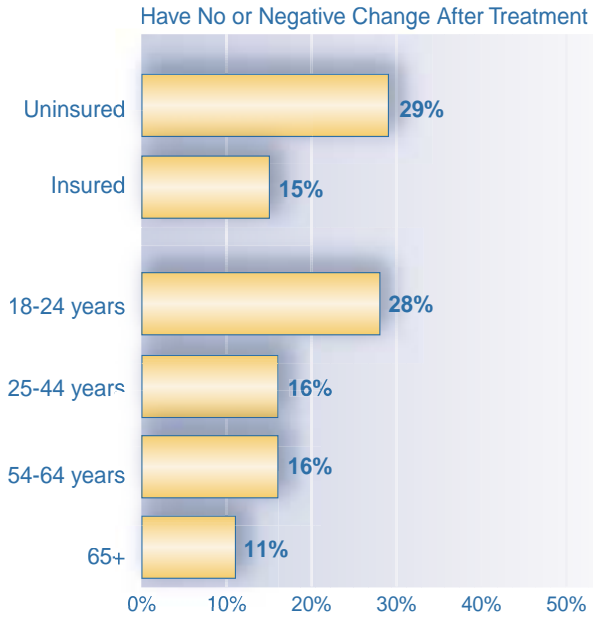
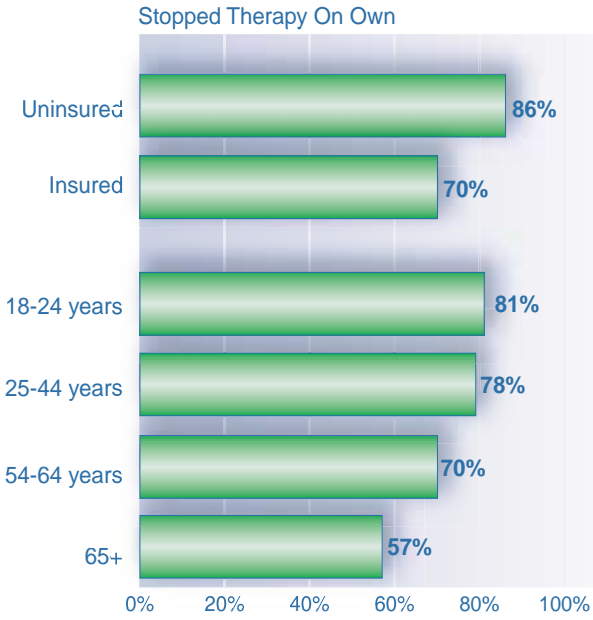
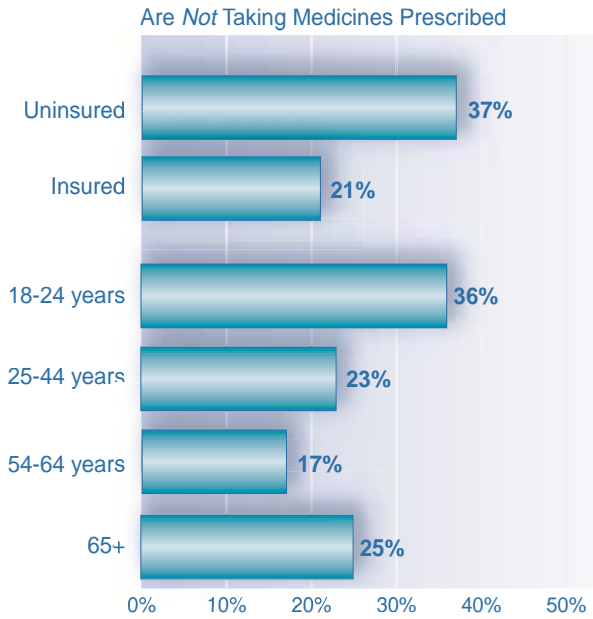
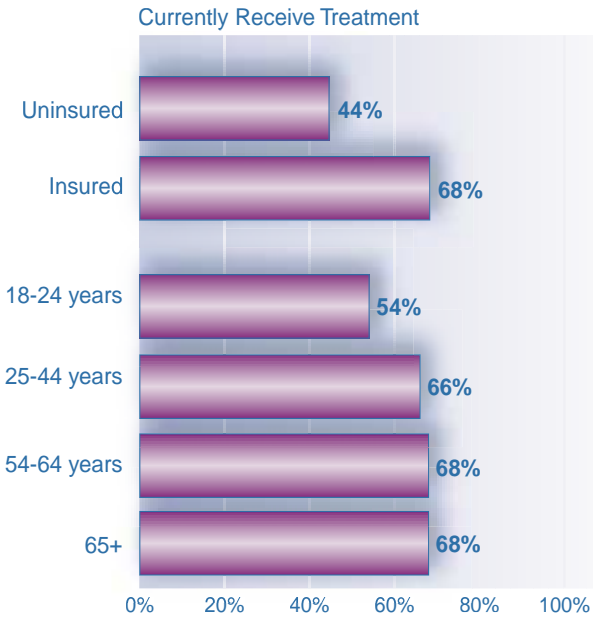
The survey data reveal a high proportion of treatment failures. Among those who have stopped therapy, close to three-fourths (73%) say they stopped for their own reasons rather than based on agreement with their provider.

Finally, approximately one in five believe their depression got worse or at best stayed the same after treatment. Those aged 18 to 24 (28%) and those who do not have insurance (29%) are again disproportionately likely to report that their depression stayed the same or became worse after treatment.



**Chart 11-14: Status of Depression Sufferers**

Percent who...



## **1.4 DO PEOPLE WITH CHRONIC ILLNESSES PRACTICE RECOMMENDED HEALTH BEHAVIORS?**

### ***Smoking***

The on-line sample surveyed reported slightly higher smoking rates than those published from other national surveys. The National Health Interview Survey reports a general adult smoking rate of 23%, and rates for asthma, diabetes, CAD, and hypertension of 27%, 19%, 17%, and 25%, respectively.

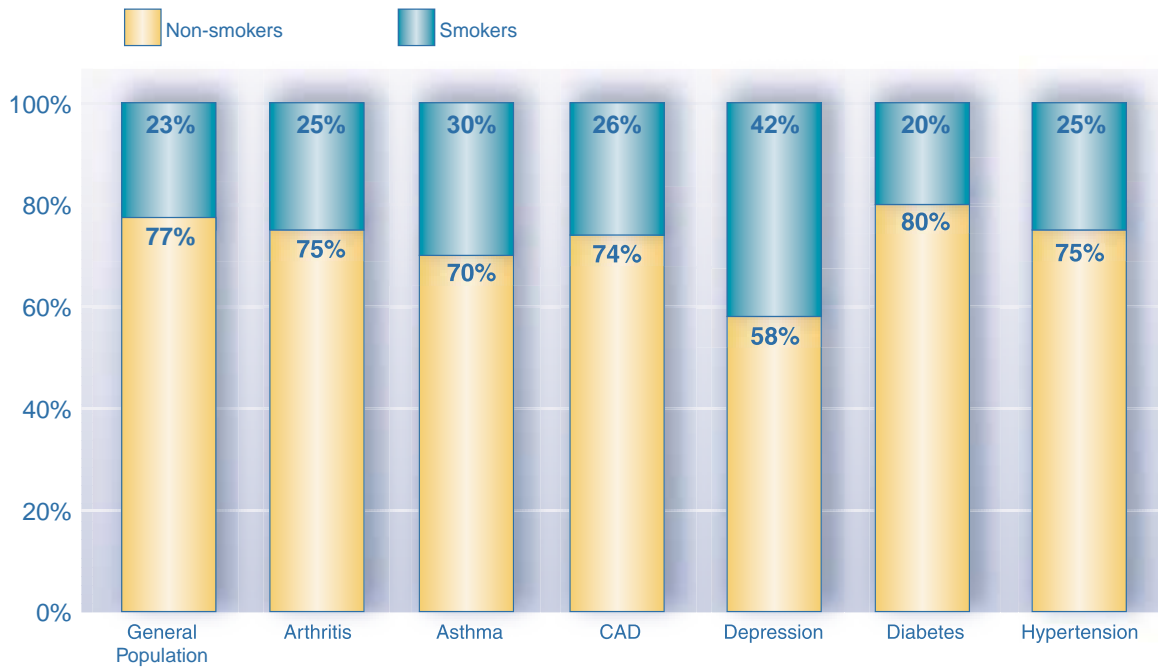
The matched chronically ill populations surveyed here reported overall smoking rates of 30%, 20%, 26%, and 25%. For our depression and arthritis samples, the reported smoking rates were 42% and 25%.

In both the NHIS and chronic survey data sets, it is striking that high rates of smoking persist among populations with specific pulmonary and cardiovascular health risks, such as asthma and coronary disease. And among those with chronic illness, smoking continues at higher rates among women, people under age 45, the uninsured, and those with lower education.

The persistence of smoking habits among these diagnosed patients – who report frequent doctor visits - highlights the need for better patient education and improved communication by doctors about preventive measures: almost one-third (31%) of asthmatics and 17% of CAD sufferers who smoke regularly have not been advised by their doctors to quit smoking. And the same population groups whose rates of smoking continue to rise – women, young people, low income people – are also least likely to be counseled by their physician to quit.

### Chart 15a: Smoking Rates Among People With Chronic Illnesses

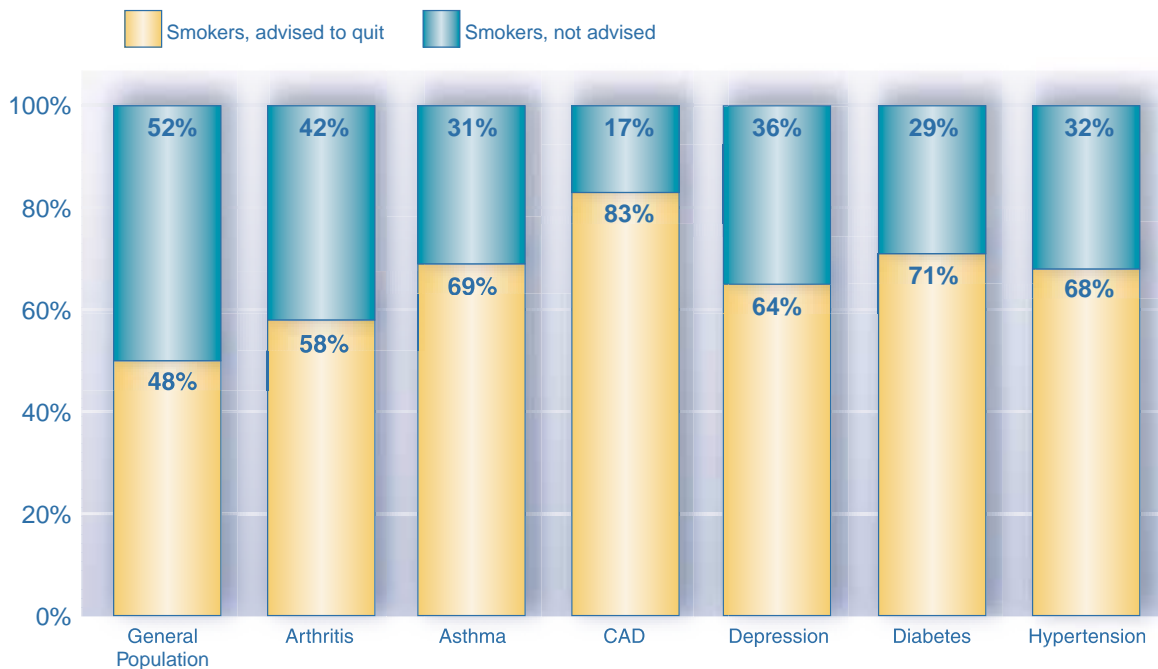
Percent of smokers and non-smokers by condition



General population data source: Behavioral Risk Factor Surveillance System, 2000. Survey data, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services. May, 2000.

### Chart 15b: Smokers Advised

Percent of smokers who received advice from doctor to quit



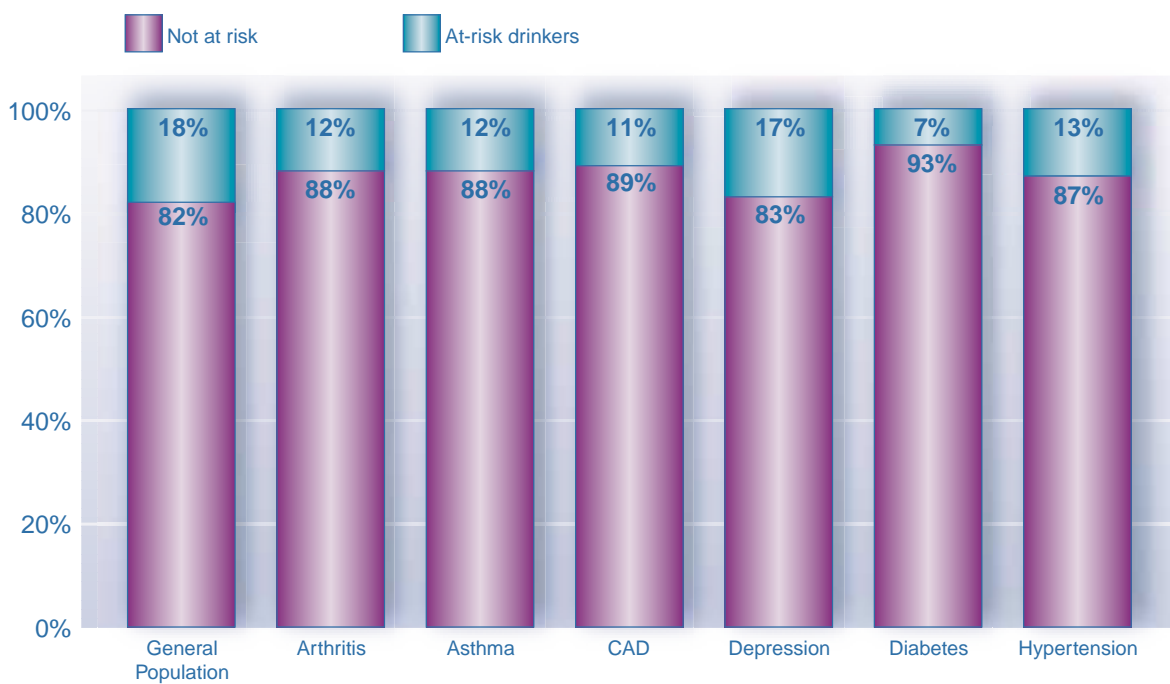
## 1.4 DO PEOPLE WITH CHRONIC ILLNESSES PRACTICE RECOMMENDED HEALTH BEHAVIORS? (CONTINUED)

### Drinking

According to the survey, eighteen percent of the general adult population is classified as at-risk drinkers<sup>6</sup>; fewer of those who suffer from a chronic illness report drinking at rates associated with alcohol misuse. Of those who are drinking at high-risk rates, few have been advised to change their habits by their doctor. Men, those aged 18 to 24, and non-whites are among those who are especially likely to be at-risk drinkers.

Physicians appear to give less attention to high-risk drinkers than to smokers (Chart 16c). When treating patients who report both smoking and alcohol misuse, doctors frequently (52%) advise the patient to change their smoking habits but not their drinking patterns. As many as one-third of those who smoke and are at-risk drinkers (35%) were not advised to change either by their doctors.

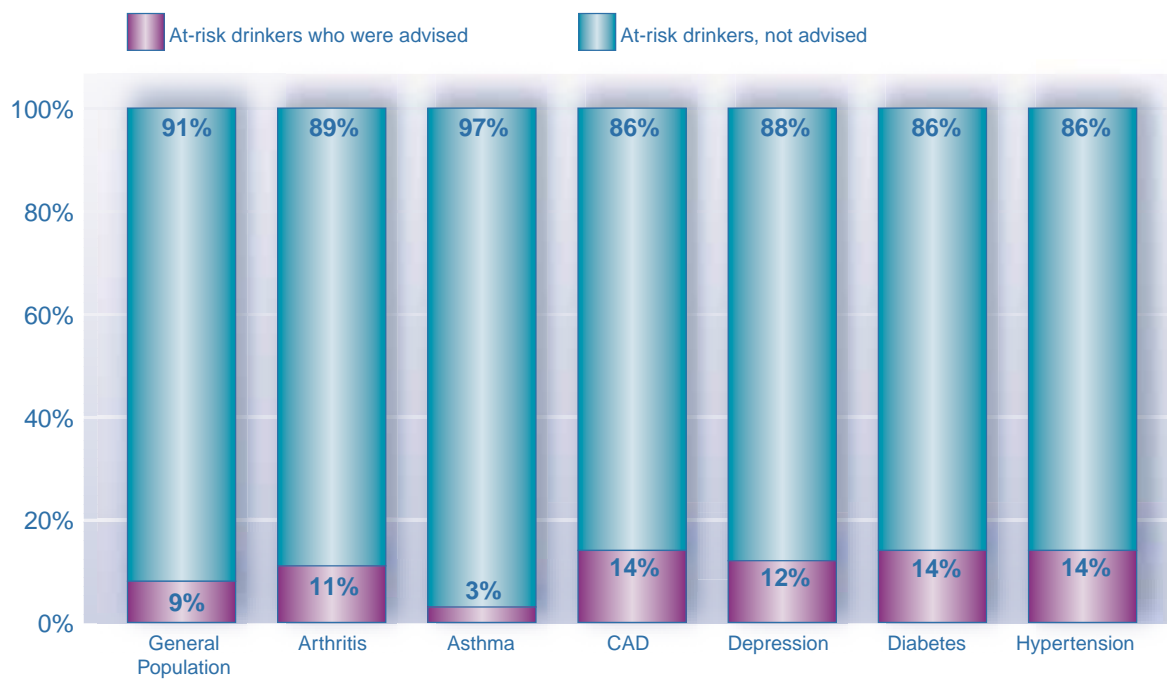
**Chart 16a: At-Risk Drinkers**



<sup>6</sup> Source for definition of at-risk drinking: Saunders JB, Aasland OG, Babor TF, de la Fuente JR, Grant M. Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO. Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption. II. *Addiction* 1993; 88(6): 791-804. A shortened version of the AUDIT scale was employed with the authors' permission for this survey. AUDIT measures take the age and gender of a respondent into consideration in defining at-risk drinkers. For example, a male must score higher than 7 on the abridged AUDIT in order to be an at-risk drinker, while a female OR a male over the age of 65 needs to score higher than 6 to be an at-risk drinker. A score of 8 can be achieved by consuming one beer every night.

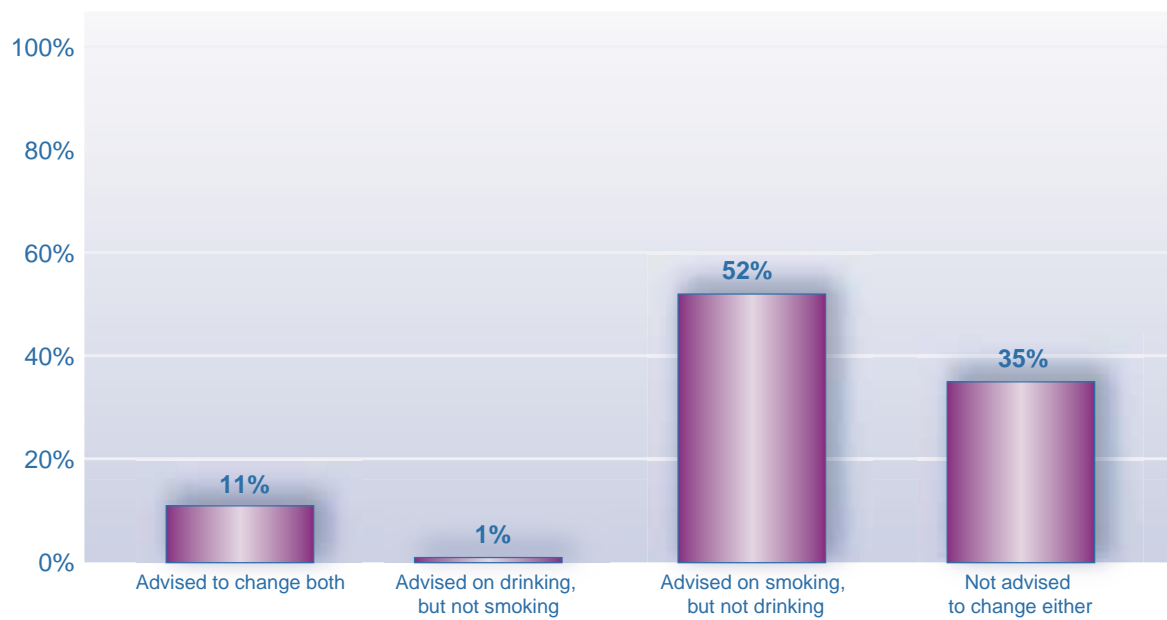
### Chart 16b: At-Risk Drinkers Advised

Percent of at-risk drinkers who received advice from doctor to change drinking habits



### Chart 16c: Smokers and At-Risk Drinkers Advised

Percent of those who are smokers AND at-risk drinkers who received advice from doctor to quit smoking/change drinking habits



Numbers do not add to 100% due to rounding.

## ***Physical Activity***

As many as 41% of those who have a chronic illness say they exercise regularly (as do 44% of the general adult population). But the actual proportion of people who exercise may be far less: in our survey, only 25% of people with chronic illnesses specifically reported that they had exercised for at least four of the last seven days, compared with 29% of the general population.

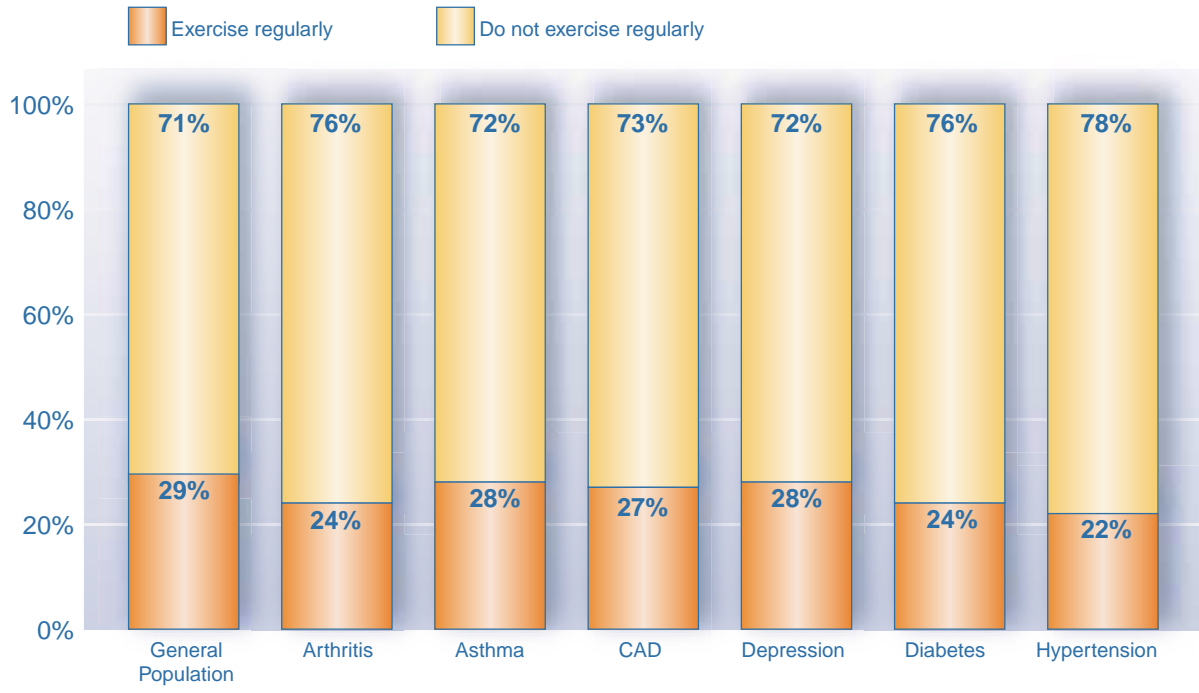
The proportion reporting regular exercise is relatively stable across the six chronic conditions and across various demographic groups as well, though the likelihood of regular exercise diminishes as age increases.

Among those who say they do not exercise, the fear of injury is mentioned by one-third as the main reason for not exercising. The prevalence of a medical or health condition (mentioned by 25%), or a lack of willpower and the lack of company to exercise with (mentioned by 10% each) are the other major reasons cited.

But as was the case for alcohol misuse and smoking, fewer than one-third of non-exercisers were advised to be more active by their doctors.

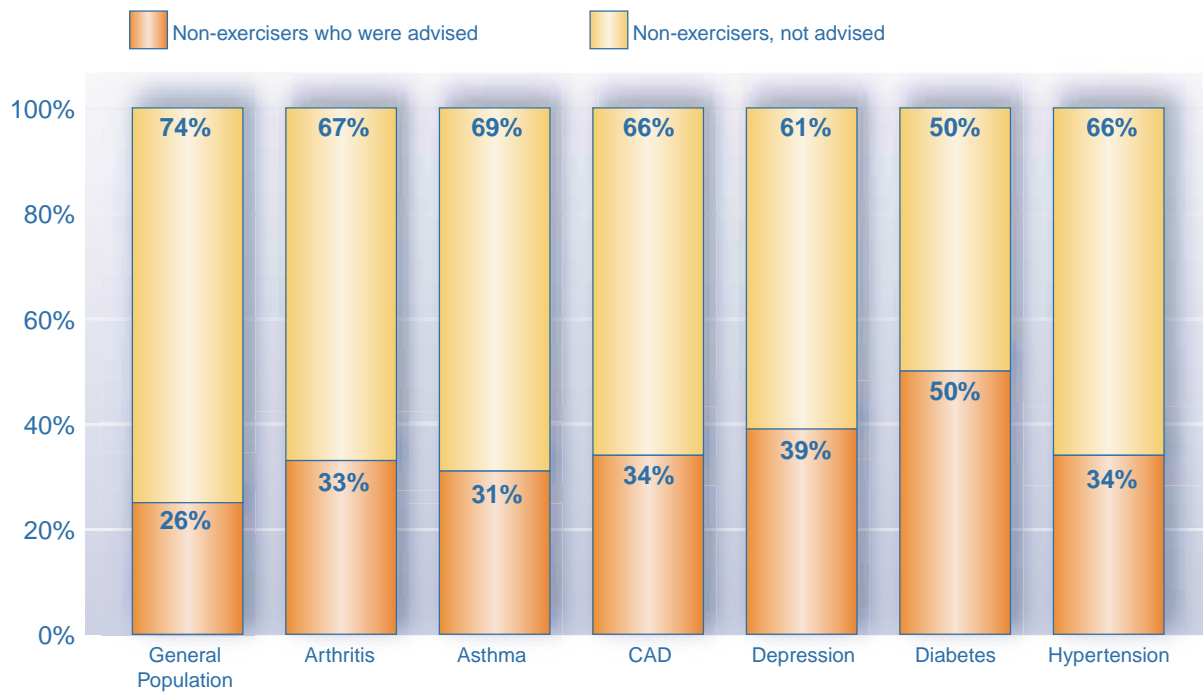
### Chart 17a: Physical Activity Among the Chronically Ill

Percent who say they exercised for at least 4 of the last 7 days



### Chart 17b: Physical Inactives Advised

Percent who do not exercise and were advised by doctor to be more active







# Access To Needed Medical Care

## OVERVIEW

Americans suffering from chronic illness are in particular need of frequent and prompt access to medical care. We found significant proportions of the surveyed population who lack both financial access – insurance coverage and affordability – as well as physical access.

Overall, 7% of chronic illness sufferers lack insurance, but the rate varies substantially, with those conditions more prevalent among the Medicare-eligible elderly population – such as arthritis and coronary disease – reporting far lower rates.

Only 6% of those surveyed do not have a regular doctor, but as many as one-fourth of young people with chronic illness lack a regular provider.

*Affordability* is a more common barrier to care than insurance coverage for the chronically ill population. Almost one in five were unable to *afford* medical care sometime during the last twelve months.

About one-fifth of those surveyed report that they were unable to schedule convenient and timely doctor appointments or encountered unacceptably long waits in the waiting room.

Many of these patients, of course, have needs beyond the brief encounter with the doctor. The frequently expressed need for home care and special transportation services remains unmet for the vast majority of patients.

### *People with chronic illness:*

- ❖ Generally have a regular doctor and have had an average of 7.4 visits in the past year
- ❖ Are somewhat more likely than the general population to have health insurance – largely because they are often older and have Medicare coverage
- ❖ Report growing difficulty with affording health care
- ❖ Have high rates of unmet needs for support services, including home care and transportation
- ❖ Who report being in poorer health are more likely to lack health insurance

## 2.1 DO PEOPLE WITH CHRONIC ILLNESSES HAVE ADEQUATE INSURANCE COVERAGE?

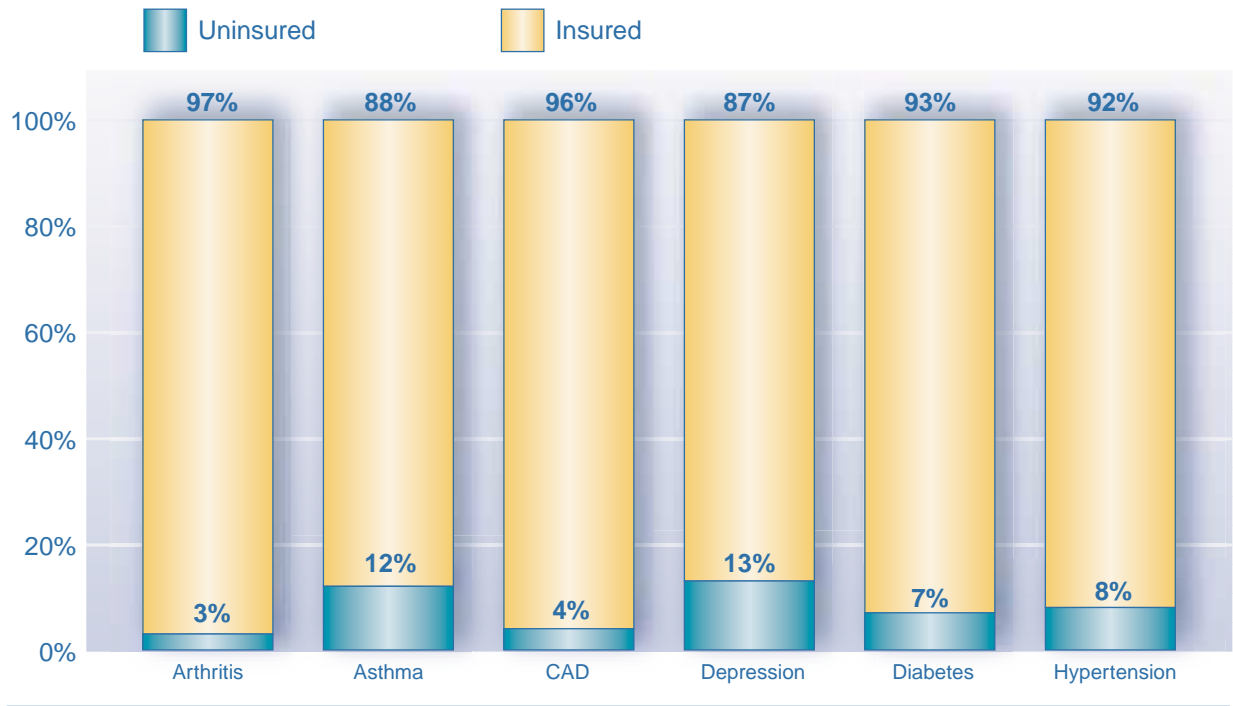
The vast majority of people with chronic illness surveyed have some form of health insurance (93%) – higher than the 85% figure observed in the general population. Though the uninsurance rate for the survey population is relatively low at 7%, 18% can recall a time in the past 12 months where they needed medical care but did not get it because they could not afford it.

The uninsurance rates for the population we surveyed varied by diagnosis, from a low of 3% among arthritis sufferers to 13% for depression patients.

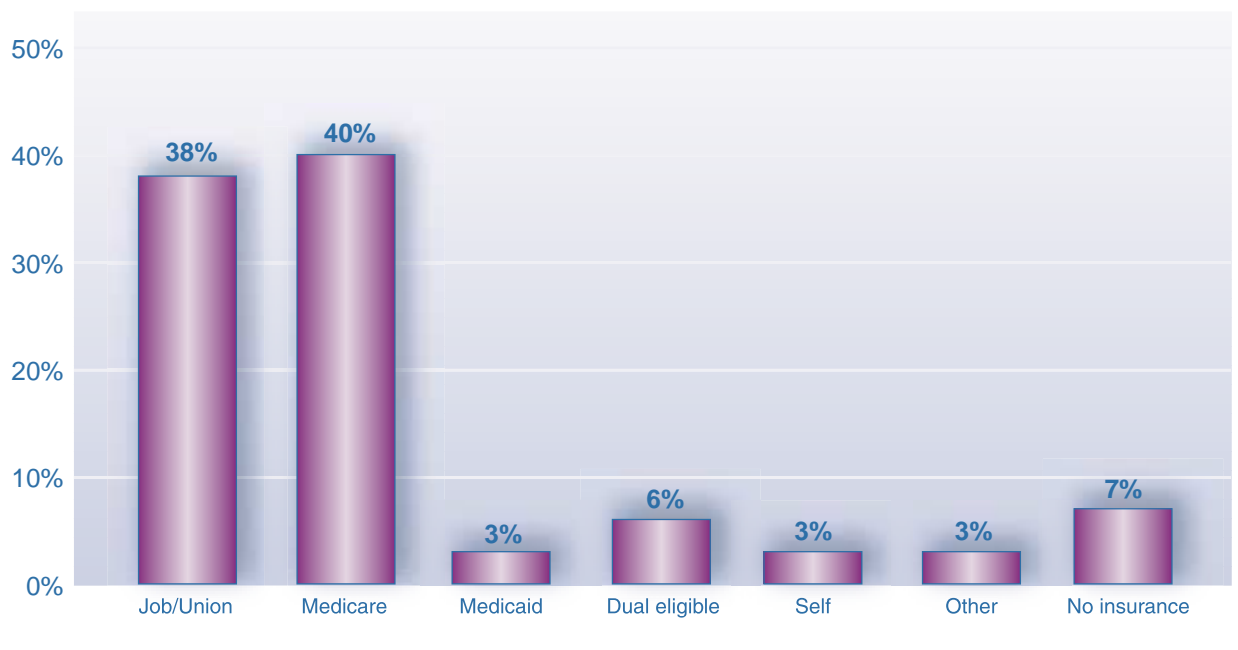
Most commonly, people with chronic illnesses either have primary insurance that is provided through their employer or union (50%), or by Medicare (29%). One-quarter (24%) also indicate they have self-purchased insurance, while 10% are covered through programs like Medicaid/CHIP.

With expected increases in premiums and coinsurance, and continued pressure on prescription drug coverage and costs, additional analysis of affordability is warranted. While most chronic illness sufferers are likely to retain some level of coverage, their need for medications and special services will make them particularly likely to experience heightened affordability problems in coming years.

**Chart 18: Insurance Care for the Chronically Ill**



**Chart 19: Primary Source of Insurance**



## **2.2 IS COST A BARRIER TO CARE FOR THE CHRONICALLY ILL?**

Among the general population, 23% indicated they were not able to get medical care sometime during the past 12 months because they could not afford it.

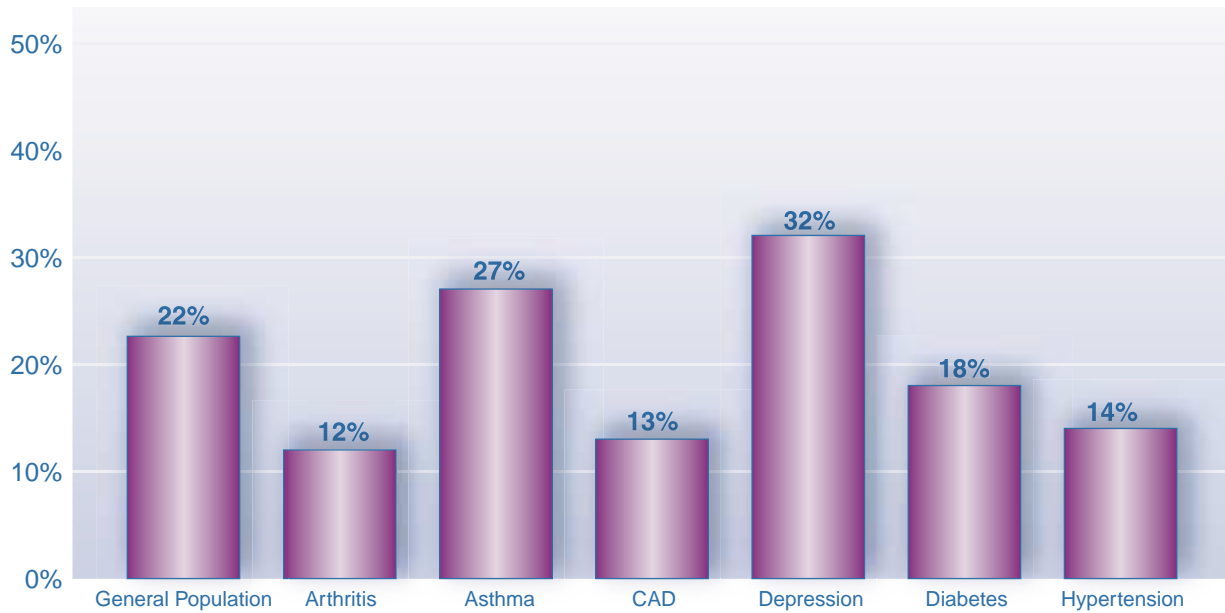
For most chronic illnesses, fewer patients say that they were unable to receive care because they could not afford it. The two noticeable exceptions are those who suffer from depression and asthma. One-third of those who suffer from depression (32%) and one-quarter of those who suffer from asthma (27%) say they have been unable to afford all their medical care needs.

In addition, African-Americans (19%) and Hispanics (26%) are more likely than their white counterparts (16%) to report being unable to afford adequate medical care.

Perhaps not surprisingly, those who currently are uninsured are the most likely to say they were not able to afford medical care some time in the past twelve months (71%). A similar concern is also voiced by two-fifths of those covered by Medicaid (39%). Comparatively, those covered by Medicaid (9%) or through their jobs (16%) are significantly less likely to report trouble in affording medical care.

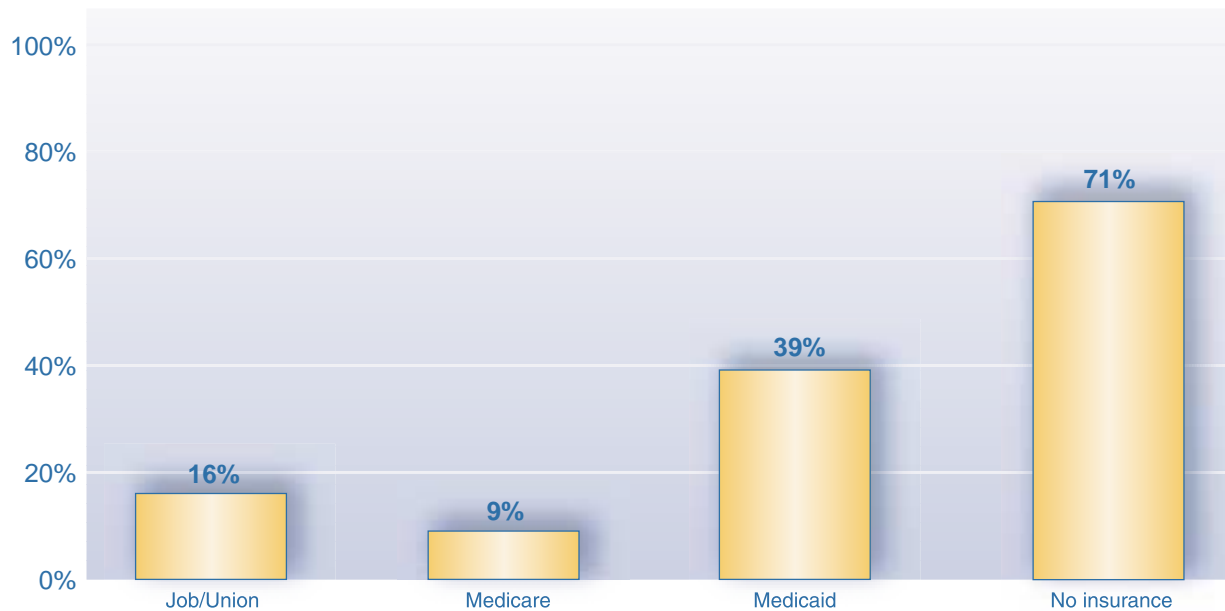
### Chart 20a: The High Cost of Medical Care

Percent who were not able to afford medical care sometime in the last 12 months



### Chart 20b: Who Cannot Afford Medical Care?

Percent within each primary insurance coverage type who say they cannot afford care



## 2.3 DO PEOPLE WITH CHRONIC ILLNESSES GET TIMELY ACCESS TO PHYSICIAN CARE?

The vast majority of chronically ill people have a regular doctor that they have met with in the past year (94%). Among the six chronic illnesses considered, those who suffer from depression (12%) or asthma (15%) are the most likely to report not having a regular doctor. People with diabetes (3%) and arthritis (1%) were very unlikely to lack a personal doctor.

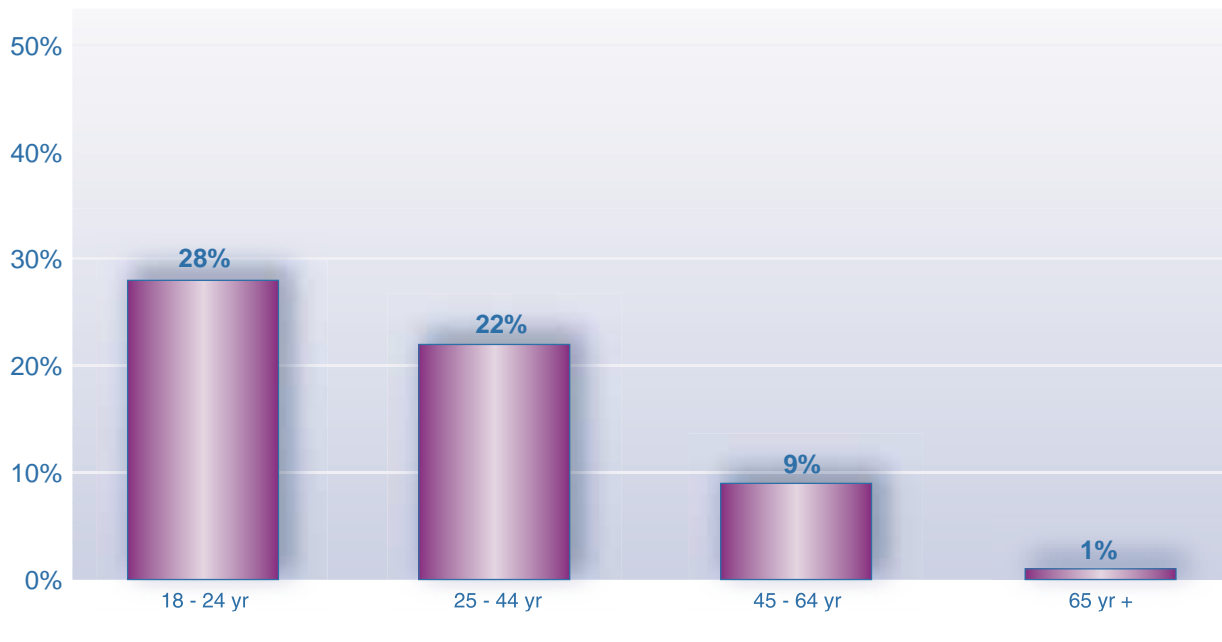
The likelihood of having a regular doctor is also affected by income and age. Those who suffer from a chronic illness and have an annual household income of less than \$15,000 (11%) are twice as likely to not have a regular doctor as those with household incomes in excess of \$15,000 (5%).

The disparity between age groups is as dramatic. People aged 18 to 24 are least likely to have a regular doctor (28% do not) while those aged 65 or older are the most likely to have one (only 1% do not have a regular doctor).

Additionally, Hispanics (12%) are more likely than other racial or ethnic groups to *not* have a regular doctor.

**Chart 21: Absence of a Regular Doctor**

Percent who do not have a regular doctor

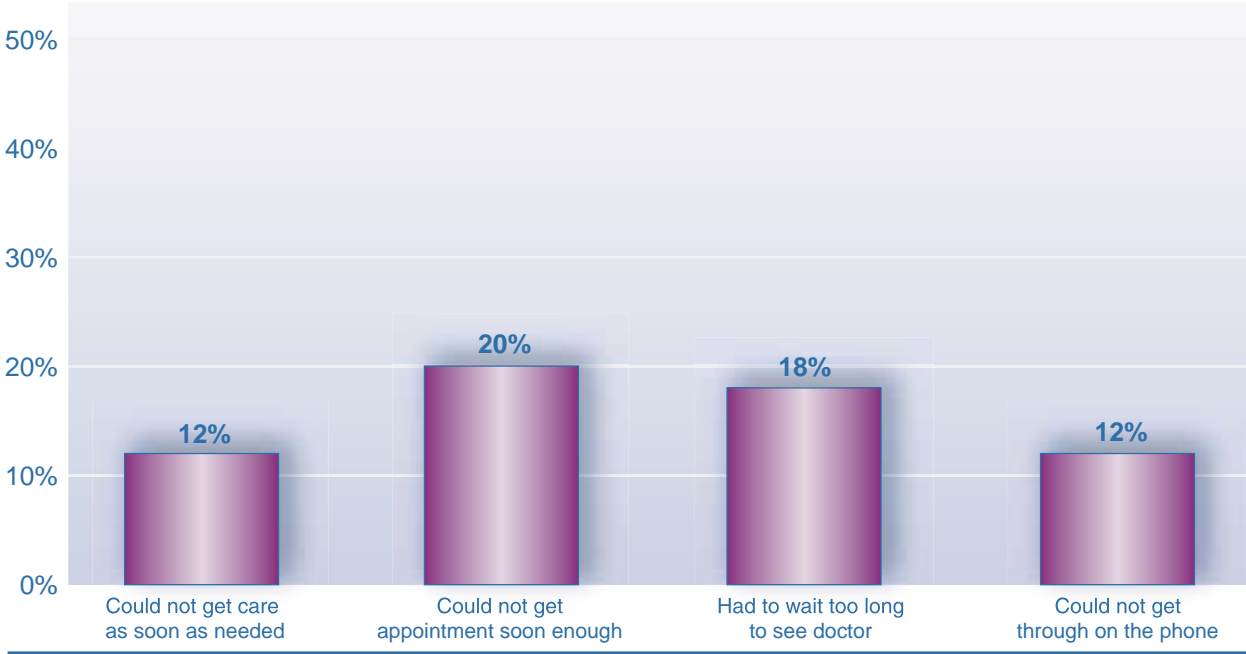


One in every eight people who suffer from a chronic illness (12%) say that at least sometimes over the last 12 months they could not get care as soon as they needed it, when they needed medical care right away. Twice as many (20%) delayed getting care because they could not get an appointment soon enough, or because they had to wait too long to see the doctor (18%) as those who lacked transportation. Another 12% say they delayed getting care sometime in the past 12 months because they could not get through over the phone.

Among those most likely to not receive timely access to care are females, those between the ages of 18 and 44 (those aged 18 to 24 are especially likely), those with annual household incomes under \$15,000, those who do not have a regular doctor, those without health insurance, and perhaps most troublingly, those who describe their health status as fair or poor.

### Chart 22: Barriers to Timely Access to Physician Care

Percent who report that sometimes in the past 12 months they...



## 2.3 DO PEOPLE WITH CHRONIC ILLNESSES GET TIMELY ACCESS TO PHYSICIAN CARE? (CONTINUED)

Virtually all people (97%) with chronic illness have seen a doctor at least once in the past twelve months and over 90% have had multiple visits with their doctor (average of 7.4 visits in the past year, vs. 4.4 visits per year by the general population).

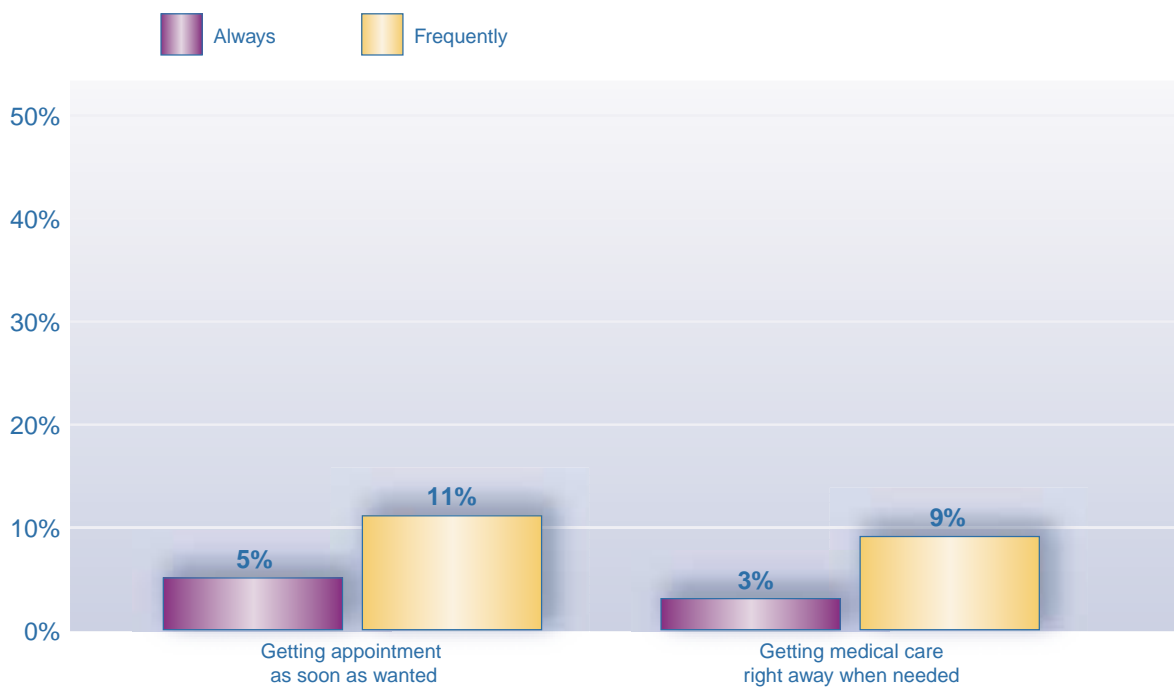
The small number (3%) who have not been to a doctor in the past 12 months are most likely to consider themselves in excellent or very good health. They are also more likely to be younger (6% of 18 to 44-year-olds have not visited their doctor vs. 2% of 44 to 64-year-olds and 1% of those aged 65 and older).

Few report persistent problems in getting a timely doctor's appointment or receiving medical care when they need it right away: only 5% say they never get an appointment as soon as they want; though twice as many African-Americans (10%) and Hispanics (11%) report this to be a problem. A higher proportion of respondents said that they sometimes had trouble getting an appointment for routine care as soon as they wanted it (11%) and a similar proportion reported trouble getting medical care right away when they needed it (9%).

Almost one in five of those with a chronic illness felt that their medical care had been delayed because they were left in the waiting room for too long (18%). Once again, African-Americans (33%) and Hispanics (30%) are disproportionately more likely than others to encounter long waits. In addition to office visits, respondents also seek advice and information from their doctors over the phone; most respondents find their doctors to be accessible in this manner.

**Chart 23: Barriers to Timely Access to Medical Services**

Percent who always or frequently have problems...

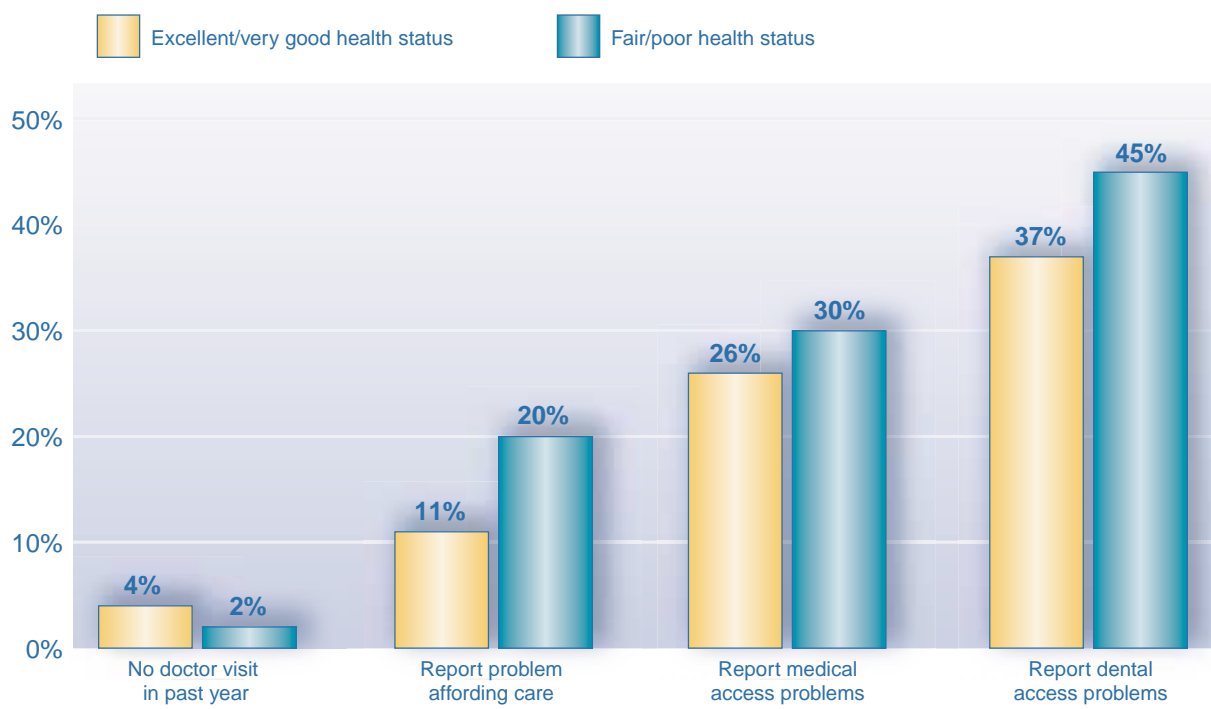




Among those surveyed, people who describe their health status as fair or poor are six times more likely to visit a doctor than those reporting excellent health status (12 annual doctor visits vs. 2 visits respectively). Perhaps because their demands for medical attention are much greater, chronically ill patients with fair or poor health status are more likely to feel they do not receive timely access to care.

For those who report poor health status, it is unclear whether their health status is poorer than others because of access problems or because they fail to get access because of the very nature and severity of their health problems.

**Chart 24: Relationship Between Health Status and Access to Health Services**



## **2.4 DO PEOPLE WITH CHRONIC ILLNESSES RECEIVE ALL THE SERVICES THEY NEED?**

Despite the substantial investment in medical services for the chronically ill, there remain serious gaps in the frequency and adequacy of support services.

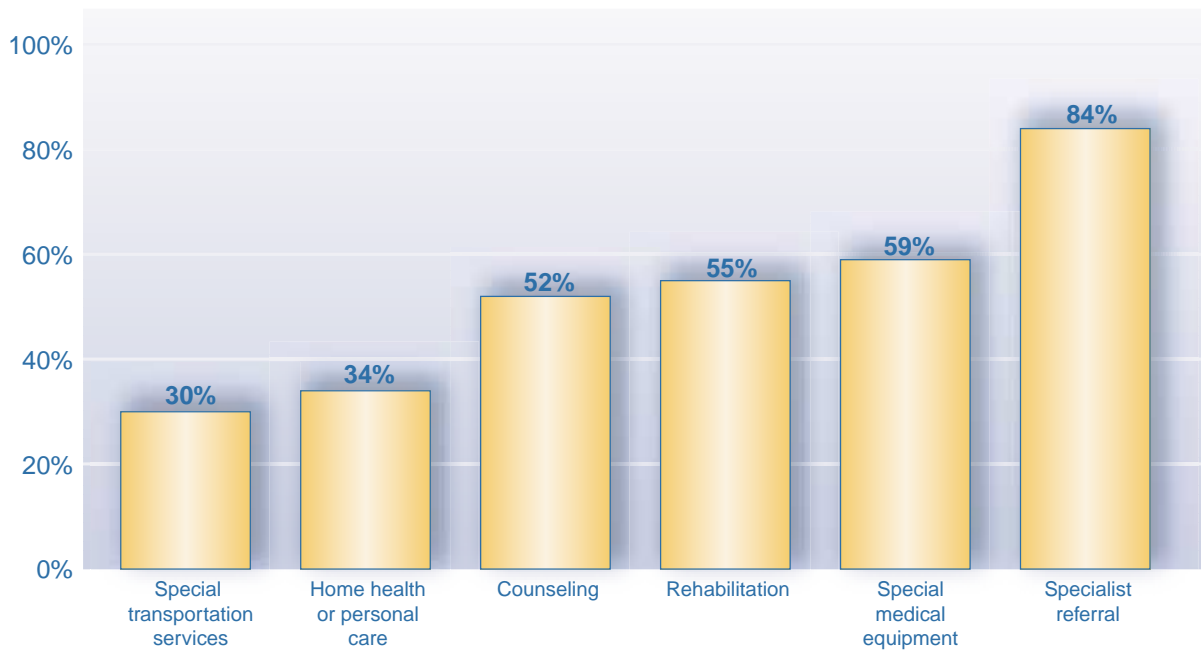
There are several stark examples of unmet health service needs among the chronically ill. Fully two-thirds of those who say they need home health or personal care, or will require special transportation services, say they do not receive such services. Approximately half of those who need rehabilitation or counseling services do not receive them, while two-fifths do not get the special medical equipment they require. Among those most likely to have unmet needs are those from households with annual incomes of less than \$15,000, those without health insurance, African-Americans and Hispanics.

The lack of health insurance is strongly related to utilizing non-medical health services:

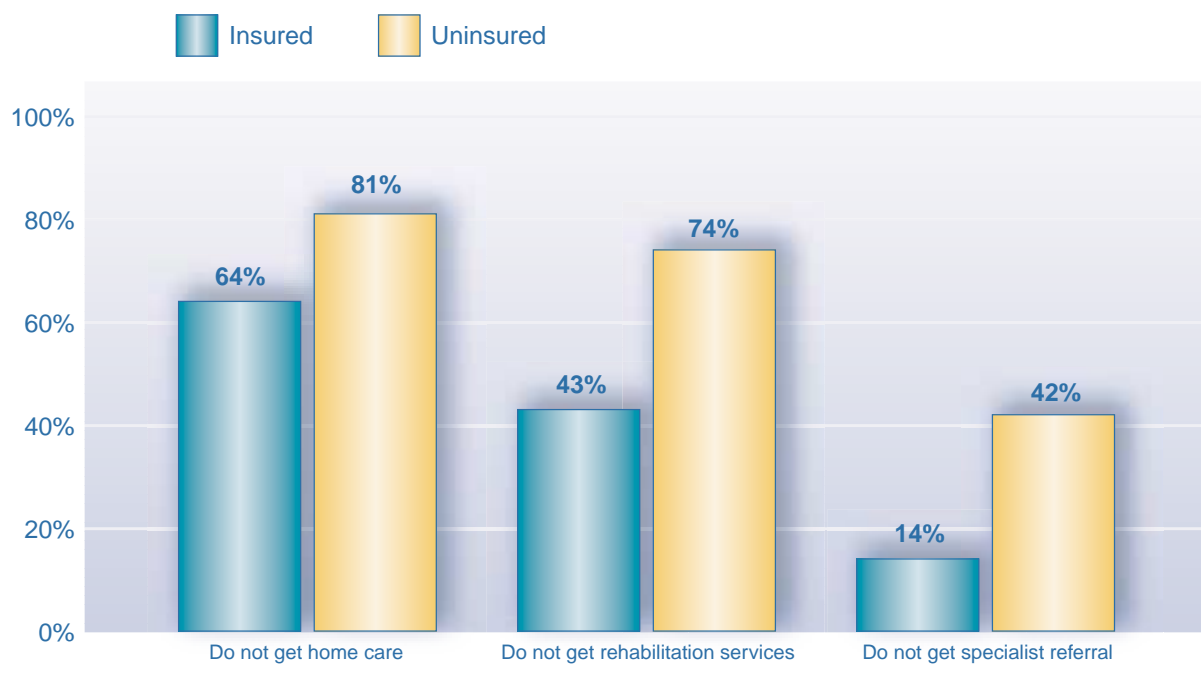
- 81% of those without insurance do not get the in-home care they need (vs. 64% of the insured)
- 74% of those without insurance do not get the rehabilitation services they need (vs. 43% of the insured)
- 58% of those without insurance do not get the referral they need (vs. 14% of the insured).

### Chart 25: Gaps in Medical Services Provided to Patients

Percent of those who need a given service who actually receive it



### Chart 26: Impact of Insurance Coverage on Receiving Medical Services



## **2.5 WHAT ARE THE MOST COMMON BARRIERS TO GETTING THE NECESSARY CARE?**

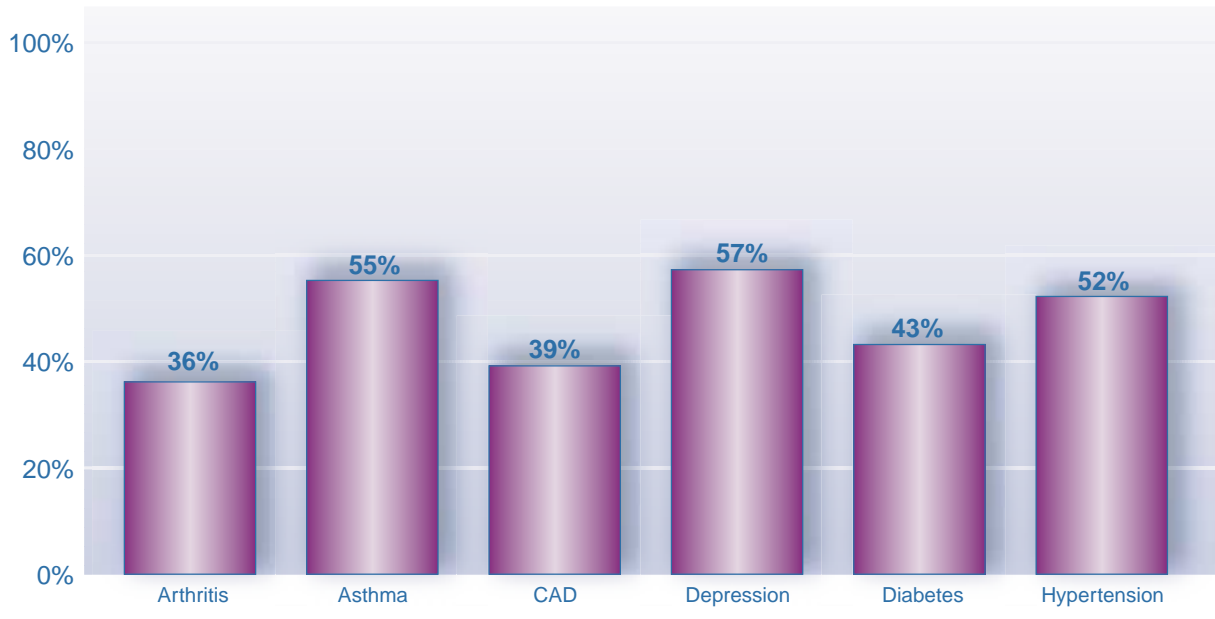
More than half of those who suffer from depression, asthma or hypertension do not have someone to help them coordinate their care when there is more than one health care provider involved. The same is also true for at least one-third of those who suffer from diabetes, coronary artery disease or arthritis.

The chronically ill face a variety of barriers to accessing medical services. These range from trouble getting medication (a problem for 28%), to help coordinating medical services (45% of those who have multiple providers say they receive no help from their doctor or health plan) and the long wait time for receiving support services (only 62% say they receive desired services within 30 days of their requesting it).

African-Americans, Hispanics and those aged 18 to 24 are the most likely to encounter these barriers.

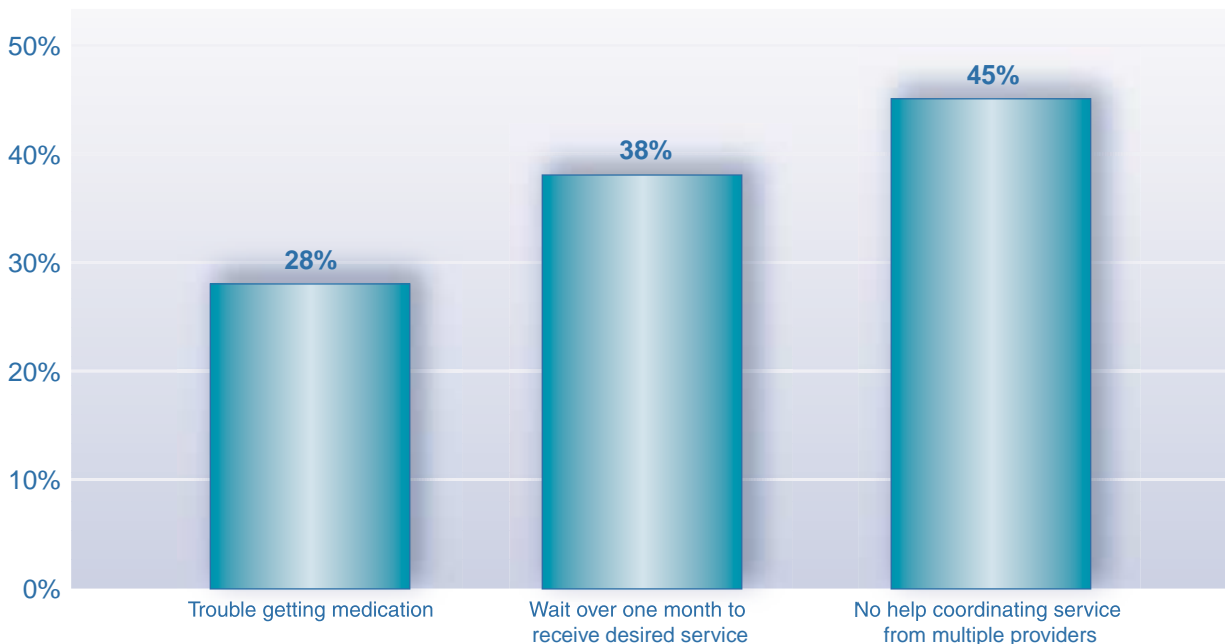
### Chart 27a: A Helping Hand Needed

Percent who do *not* have someone to help them when there is more than one health care provider involved



### Chart 27b: Commonly Encountered Barriers

Percent who encountered each of the following obstacles





# Receiving Appropriate Medical Care

## OVERVIEW

Since the mid-1980s, professional societies and consensus panels have published numerous guidelines for proper care of those with chronic illness. Many elements of these guidelines can be accurately reported by patients themselves – whether doctors have counseled them on specific practices, taught them and observed them in monitoring key indicators, conducted specific tests, and provided specific treatments.

A similar set of recommendations exists for the general adult population as well. The U.S. Clinical and Preventative Services Task Force has published consensus standards for screenings, education, and immunizations for each age-sex and risk group in the population, many of which can be assessed through patient surveys.

Our surveys compared patients' experiences with the published professional standards. In some areas, quality of care appears to be high, such as helping asthma patients understand their care plan and engaging depression sufferers in counseling. But some of the shortcomings are surprising and basic in nature.

Doctors often fail to adequately advise their patients about disease-specific health maintenance and wellness strategies. Two-thirds or more of chronically ill patients who need such counseling have never been encouraged by their doctor to exercise; one-third of smokers have not been advised to quit. On average, doctors did not properly advise at least one-third of their patients on wellness strategies who suffer from any given condition.

Some of the very populations that are traditionally deemed most at-risk continue to report the biggest unmet needs. Minorities (Hispanics in particular) and those who are poor or under age 25 are less likely to have received appropriate levels of care, information and attention from their doctors.

### *People with chronic illness:*

- ❖ Do not get advised by their doctor to make healthy behavior changes about two-thirds of the time
- ❖ Do not get recommended condition-specific tests and treatments about one-half of the time
- ❖ Do not get enough information to manage their own health about one-third of the time

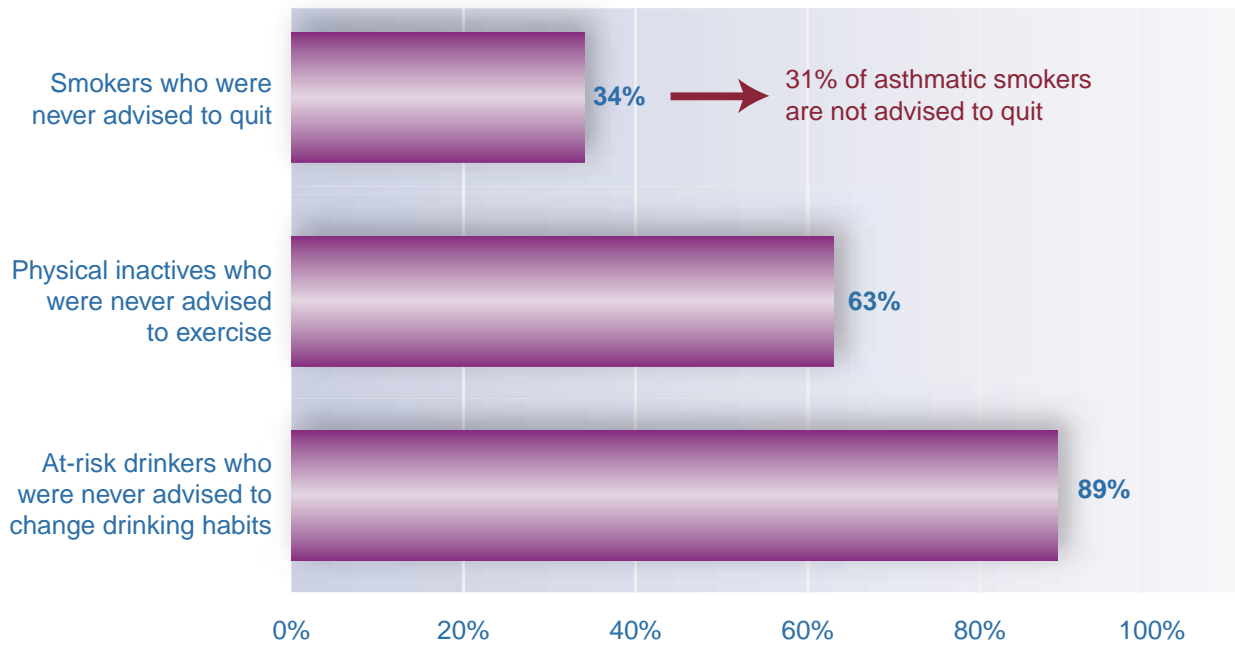
### 3.1 ARE DOCTORS ADVISING PEOPLE WITH CHRONIC ILLNESSES ABOUT NEEDED CHANGES IN HEALTH BEHAVIORS?

More than one-third of people who are chronically ill and smoke have not been counseled by their doctors to quit. Even in the face of serious respiratory illness, 31% of asthmatic smokers reported that their doctors had not asked them to stop smoking.

Similarly, two-thirds of those who lead a sedentary lifestyle have never been asked to increase their regular physical activity. Doctors appear to be particularly reluctant to advise their chronically ill patients at high risk for alcohol misuse to monitor their drinking habits -- only 11% were advised to do so.

**Chart 28: Missed Opportunities**

Percent who were never advised against (specific) risky behavior





## 3.2 ARE DOCTORS EDUCATING PEOPLE WITH CHRONIC ILLNESSES HOW TO CARE FOR THEMSELVES?

Practice guidelines for chronic illness emphasize the importance of self-care education. The guidelines recognize that infrequent and brief visits to the doctor cannot substitute for active monitoring of key indicators such as peak flow, blood pressure, and blood glucose. And many patients need to use and manage their medication programs carefully to avoid complications.

About two-thirds of all chronic populations surveyed report appropriate levels of counseling on self-care from their physician. Many others, despite being counseled, report remaining confused and unable to perform basic self-care activities after leaving the doctor's office.

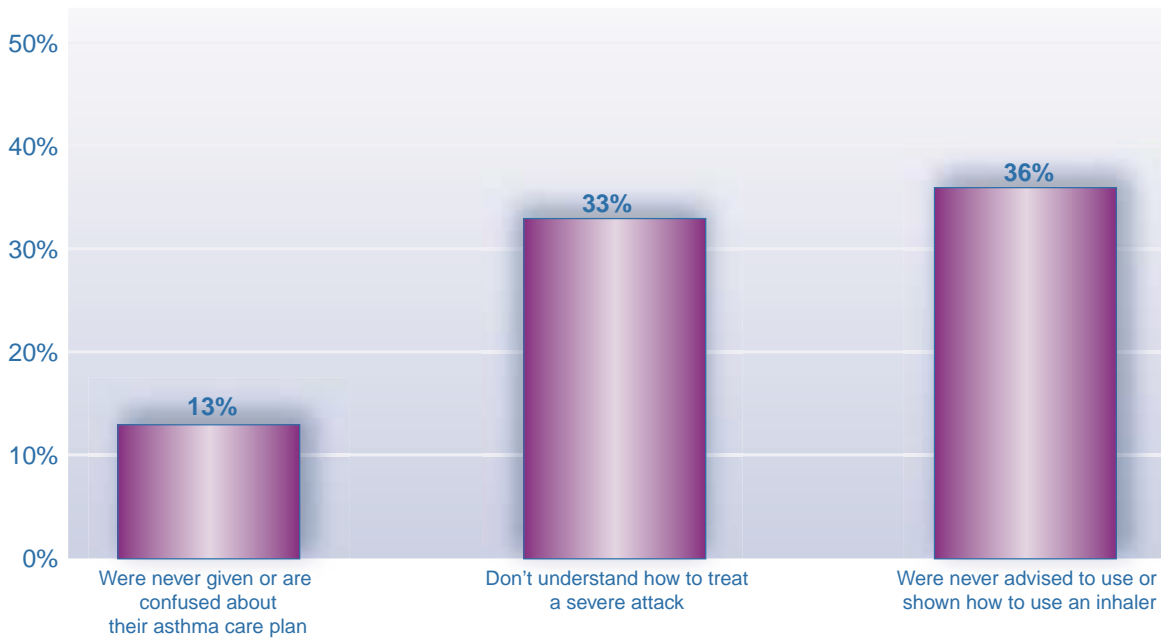
### **Asthma**

Doctors miss many opportunities to empower asthma sufferers to take better care of themselves and educate them on necessary health management strategies. One-third of asthma patients have not been shown how to use an inhaler or what to do in case of a severe attack. Virtually all (99.5%) of moderate to severe asthmatics have been advised to use a peak flow meter regularly, but 82% report that they do not do so. At least one in ten of surveyed asthma patients say they remained confused about or were never given a written asthma care plan.<sup>5</sup>

The rates of poor compliance with asthma practice guidelines are greater for Hispanics and the uninsured, two groups with disproportionately high – and growing – rates of asthma.

**Chart 29: Are Doctors Following Asthma Treatment Guidelines?**

Percent of patients who...



<sup>5</sup> The factors assessed here are based on the National Asthma Education and Prevention Program Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma. NIH Publication No. 97-4051. Available at <http://www.nhlbi.nih.gov/guidelines/asthma/asthdln.htm>.

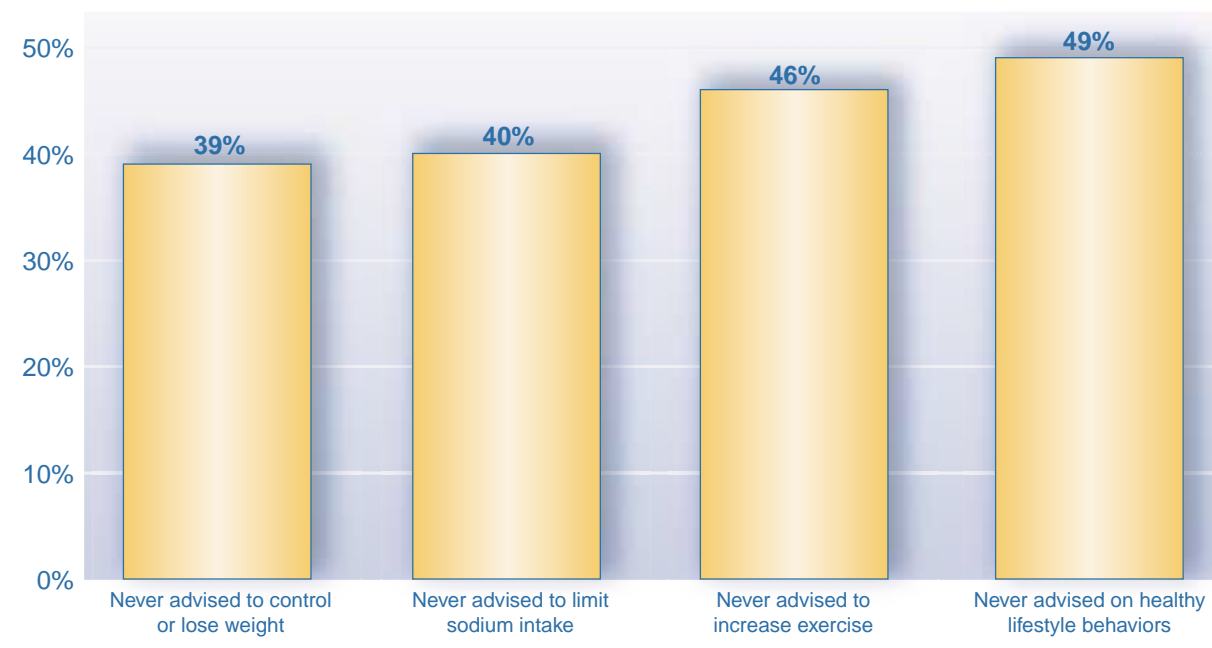
## Hypertension

Relative to other conditions, hypertension patients report the lowest levels of physician compliance with practice guidelines.<sup>6</sup> For example, approximately half of hypertension sufferers have not been advised to make lifestyle changes or exercise more. One-third have not been advised to watch their weight; two-fifths have not been advised to limit their sodium intake.

Interestingly, those who are white are somewhat less likely than others to have been told about the various ways to help manage their condition.

**Chart 30: Are Doctors Following Hypertension Treatment Guidelines?**

Percent of patients who were...



<sup>6</sup> The factors mentioned in this paragraph are based on Smith SC Jr, Blair SN, Criqui MH, Fletcher GF, Fuster V, Gersh BJ, Gotto AM, Gould KL, Greenland P, Grundy SM, et al. Preventing heart attack and death in patients with coronary disease. *Circulation* 1995 Jul 1;92(1):2-4.

**Coronary Artery Disease (CAD)**

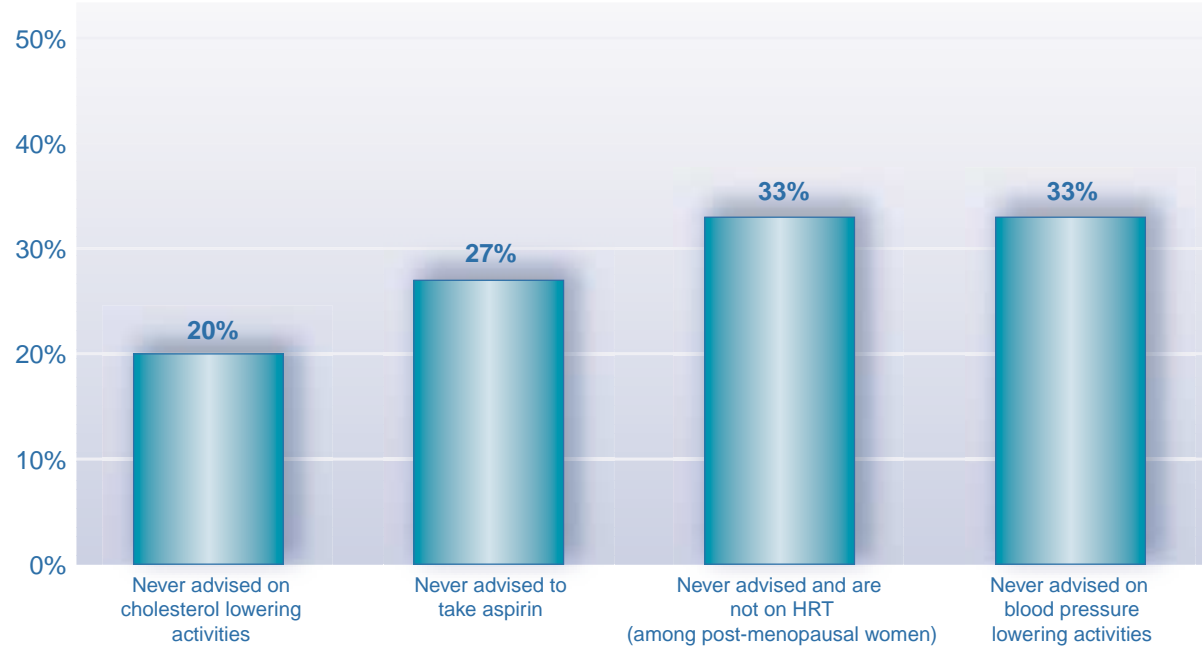
The American Heart Association has identified several recommendations for people with a history of coronary heart disease – a previous heart attack, coronary intervention, or established angina.

About one-fourth of those suffering from CAD<sup>7</sup> have not been advised on the importance of taking aspirin, and one-third have not been advised on taking steps to reduce their blood pressure.

About two-thirds of women with established coronary disease have been advised to consider hormone replacement therapy.

**Chart 31: Are Doctors Following CAD Treatment Guidelines?**

Percent of patients who were...



<sup>7</sup> Defined for the purposes of this survey as persons who say they suffer from coronary heart disease, angina or have suffered a myocardial infarction (or heart attack).

## Depression

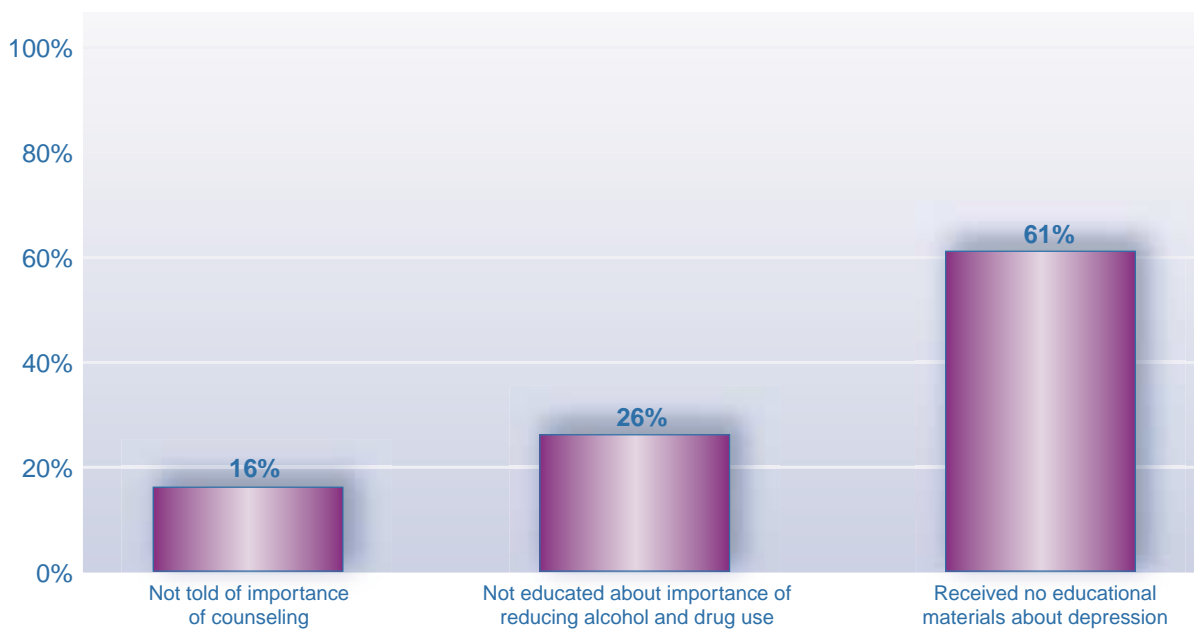
Close to two-thirds of people who are chronically depressed were never provided any depression-related educational materials. Additionally, one-quarter have not been educated about the importance of reducing alcohol or drug use, while as many as 16% were never told about the importance of counseling.

Over one-third of depression sufferers (35%) are currently not receiving treatment for their condition.

Among those who stopped therapy, three-fourths can be classified as treatment failures, i.e., they chose to stop treatment without the endorsement of their counselor.

### Chart 32: Are Doctors Following Depression Treatment Guidelines?

Percent of patients who were...

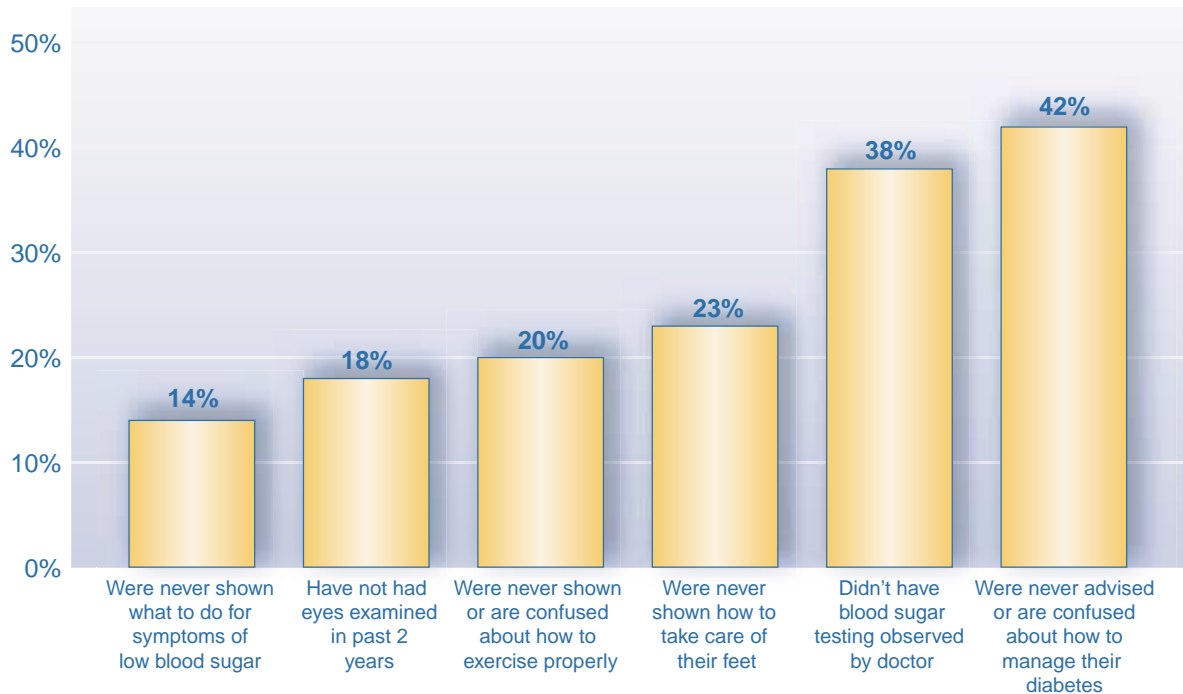


## Diabetes

As many as 42% of all diabetics surveyed report being confused or were never advised on how to manage their diabetes. This overall rating is reflected in the variable provision of concrete, guidelines-based services. For example, 38% say their doctor has not observed them conducting a blood sugar test; 20% were never shown how to take care of their feet or how to exercise properly.

**Chart 33: Are Doctors Following Diabetes Treatment Guidelines?**

Percent of patients who...





# Working As Partners With Doctors

## OVERVIEW

Successful care for chronic illness reflects a partnership between several parties – the person suffering, their family and support system, and a variety of professionals. So much of good health for those with chronic disease reflects the patient’s own ability to moderate behaviors that aggravate their health problems, monitor key health indicators, manage their own medications, and take advantage of appropriate medical services. People with chronic illness need a responsive medical system, a network of friends and family, and a positive sense of their own ability to manage their health.

We conceptualize this partnership capability in three ways: whether people feel a sense of self-efficacy, whether they are able to get necessary support from family and friends, and whether they can communicate effectively with their doctors.

Overall, the population of chronically ill Americans reports levels of self-efficacy comparable to the general public. Only the population suffering from depression reported a significant deficit. Similarly, the chronically ill do report common feelings of social isolation – but not at levels different from the general public. Those who describe their health status as poor are significantly less likely to feel that they have overall control over their lives.

Only 50% feel that their doctor offers them choices, discusses pros and cons, takes their preferences into account and asks patients for their treatment preferences on a consistent basis.

Perhaps most importantly, a feeling of consistent collaboration with their doctor is missing for up to half of all chronically ill people.

### *People with chronic illness:*

- ❖ Generally feel able to manage their illness
- ❖ Feel they are not adequately involved in making health care decisions about half the time
- ❖ Do not feel confident about their relationship with their doctor about half the time
- ❖ Are more likely to report being disconnected from their doctor and the health system if they are low income, suffer from depression, or report poorer health status

## 4.1 CAN PEOPLE WITH CHRONIC ILLNESSES TAKE CARE OF THEMSELVES?

There is evidence to demonstrate that too many chronically-ill patients are not equipped to deal with their medical conditions. According to the survey, for something as basic as deciding when it is appropriate to see a doctor, only 68% feel very confident about their ability to do so. Similarly, one-fifth are not very confident about taking their medicines in an appropriate manner and close to half have a similarly low level of confidence about eating right. Younger people, African-Americans and Hispanics are all more likely than others to report lower levels of self-confidence in managing their own health.

We asked respondents to rate their agreement with a battery of eight items which produce an "internal locus of control" score.<sup>8</sup> Responses to each of these eight items, which were provided on a seven-point scale, were transformed into a score ranging between zero and one hundred. The higher the score, the more likely one is to feel s/he has overall control over their life.

The average score for all people with chronic illnesses was 69, not significantly different from the average score of 70 reported by the general population. Only the depression population reported a significantly lower mean locus of control score (56).

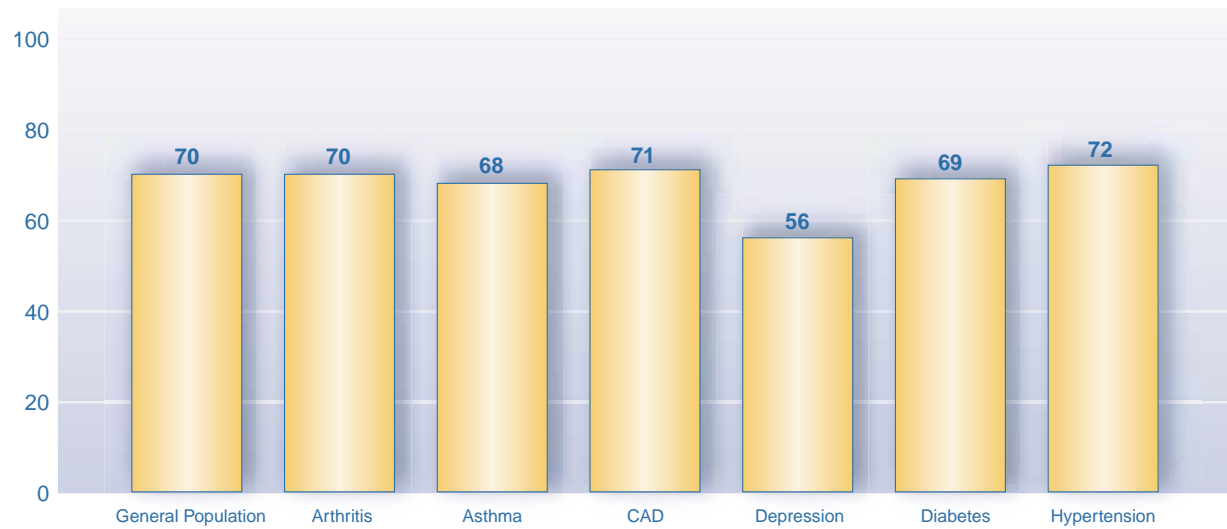
Internal locus of control scores were found to be correlated to health status. Specifically, higher scores were more likely to be reported by those who felt their health was excellent or very good (these people reported an average score of 77), while the lowest scores were reported by those who described their health condition as fair or poor (average score of 61). A similar correlation was also observed in the case of income – higher incomes are correlated to higher scores.

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<sup>8</sup> The following items comprised the scale: There is really no way I can solve some of the problems I have; I feel that I am being pushed around in life; I have little control over the things that happen to me; I can do just about anything I set my mind to; I feel helpless in dealing with the problems of life; What happens to me in the future mostly depends on me; and, There is little I can do to change many of the important things in my life.

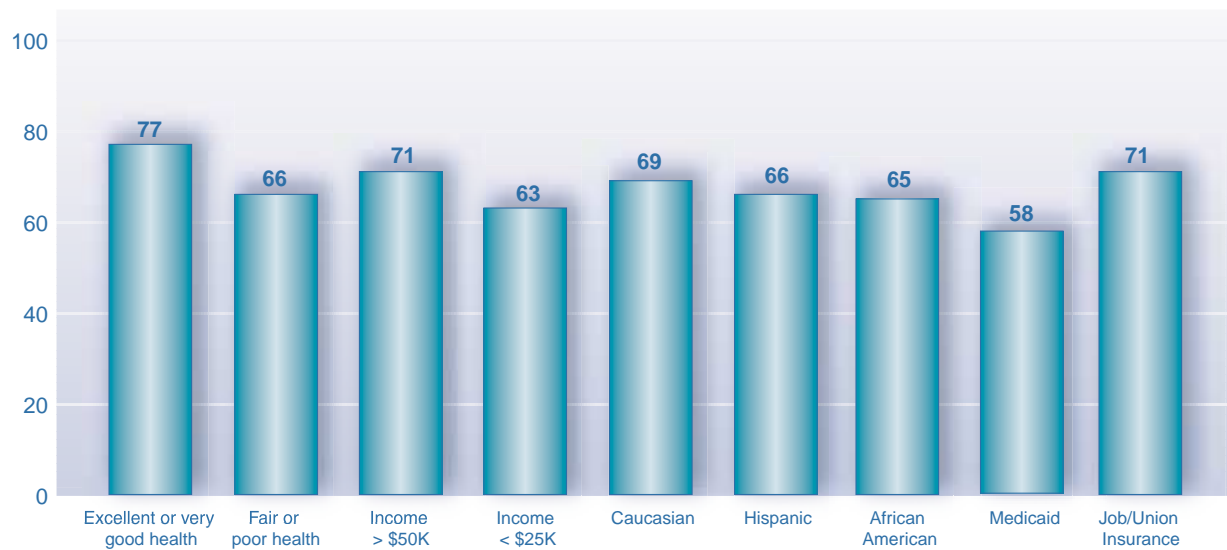


**Chart 34a: Perceptions of Control Over Life**



Note: Scores range from 0 to 100. The higher the score, the more likely one is to feel that s/he has overall control over their life.

**Chart 34b: Perceptions of Control Over Life**



Note: Scores range from 0 to 100. The higher the score, the more likely one is to feel that s/he has overall control over their life.

## **4.2 ARE PEOPLE WITH CHRONIC ILLNESSES GETTING THE NECESSARY HELP FROM FAMILY AND FRIENDS?**

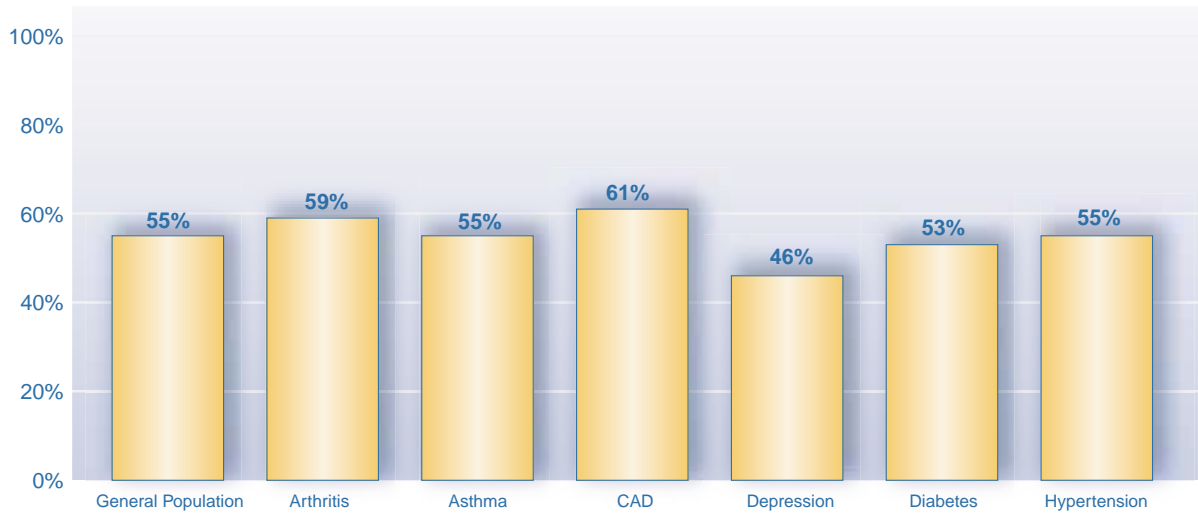
When people are sick, a high proportion of those suffering from chronic illness feel that they cannot count on friends or family to help with everyday chores (21%), housekeeping (25%) or moving (23%). When respondents are asked about getting help in an emergency, they are more often able to identify someone: only 7% feel they would have trouble finding someone to come and get them if they were stranded 10 miles from home.

Only about half of the chronically ill can count on a high level of social support, i.e., they indicate they would be supported in all four ways mentioned above. Those who are depressed are least likely to report adequate social support, while those suffering from coronary artery disease or arthritis are likely to have higher levels.

Social support scores were higher among the elderly and among African-Americans. Those who report excellent or very good health status are also more likely to report available social support, while those in poor health and those with low incomes are the least likely.

### Chart 35a: Social Support

Percent who indicate having help with all four scenarios\*

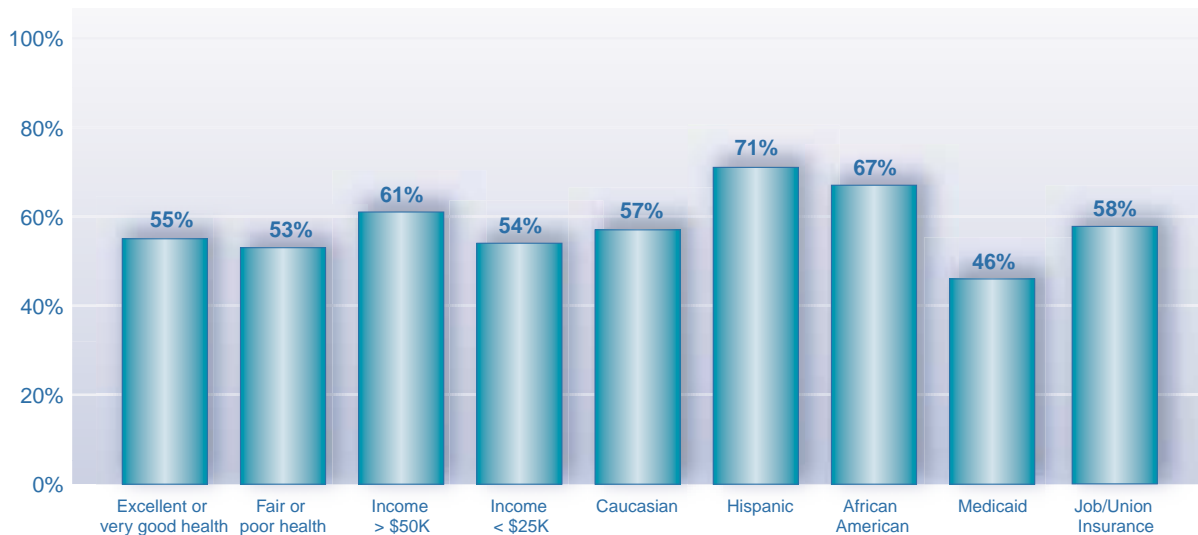


\*The four scenarios are:

- Finding help with everyday chores if sick
- Help with housekeeping
- Help with moving
- Finding someone to come and get them if stranded 10 miles from home

### Chart 35b: Social Support

Percent who indicate having help with all four scenarios\*



\*The four scenarios are:

- Finding help with everyday chores if sick
- Help with housekeeping
- Help with moving
- Finding someone to come and get them if stranded 10 miles from home

### 4.3 ARE PEOPLE WITH CHRONIC ILLNESSES COMMUNICATING EFFECTIVELY WITH THEIR DOCTORS?

People with chronic illnesses feel good about their ability to communicate effectively with their doctors. The vast majority (86%) rates their doctor favorably on setting clear goals for treatment and ensuring they understand how to monitor and treat their condition themselves.

Other evidence affirms this positive view of doctor communications. For example, most say their doctors have been helpful in making them understand what they need to do for their health (84%) or have helped keep them motivated (68%).

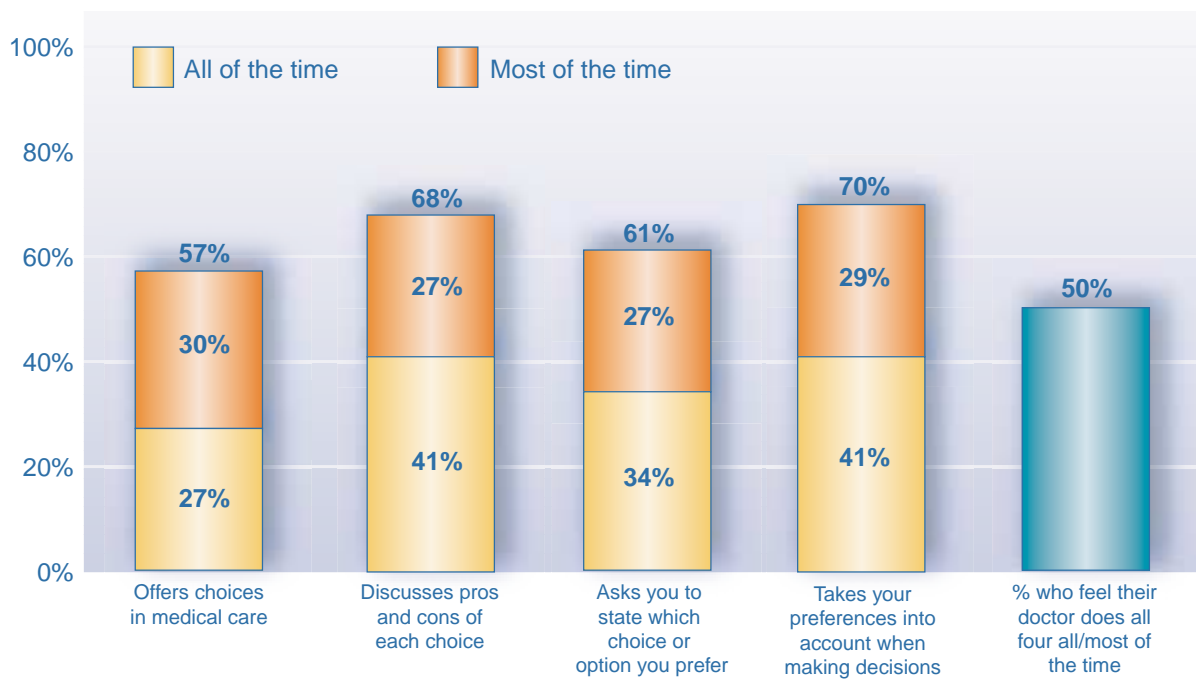
While the overall rating of communication is good, half (50%) feel that their doctor offers them choices, discusses pros and cons, takes their preferences into account and asks patients for their treatment preferences on a consistent basis.

These discrepant findings are similar to those from other research. Satisfaction surveys often report very favorable ratings of overall communications and relationship, while questions about specific services indicate shortcomings.

Among those who are least likely to feel adequately involved by their doctor in decision-making are the young, the poor, and the uninsured and Hispanic patients.

**Chart 36: Level of Patient Involvement in Decisions**

Percent who say their doctor “all of the time” or “most of the time”...



# About The Survey

## BACKGROUND

The Robert Wood Johnson Foundation National Strategic Indicators Project was designed to address two broad objectives:

- To provide RWJF with a snapshot of health and healthcare today in America
- To establish baseline indicators of health system performance in major topical areas in which the Foundation operates.

The project sought to develop a stable hierarchy of measures to guide program planning and evaluation. It followed the Consumer Information Framework developed by the Foundation for Accountability and is endorsed by the Institute of Medicine in its report, *Envisioning a National Quality Report*. The National Strategic Indicators Project uses established survey research items and scales, groups them into computed performance measures that represent understandable concepts of interest to the public, and aggregates those measures into broad concepts that address policy goals for the health system – such as delivering evidence-based (i.e., appropriate) care or improving health behaviors. The intermediate categories of measurement used in the overall project are summarized in Table 1.

**Table 1: Health and health care quality topics addressed across each of the seven online samples** (note: additional concepts addressed for teenagers and the caregiver/end of life care surveys are not fully summarized here)

Outcome Measures	Process Measures	Access to Care Measures	Consumer Empowerment Measures
1. Health Status and Quality of Life ✓ Reported health status ✓ Days lost due to poor health ✓ Social isolation status 2. Healthy Life Style ✓ Smoking ✓ Risky drinking ✓ Physical Activity 3. Self -Efficacy ✓ Confidence to care for own health	4. Getting Appropriate Care ✓ Clinical tests, procedures and medications 5. Risk Reduction Counseling ✓ Advice to quit smoking, engage in physical activity and stop risky drinking 6. Education and Teamwork ✓ General self care education and support ✓ Condition specific patient education ✓ Coordination of care ✓ Shared decision making/involvement	7. Getting Needed Care ✓ Rating ease of access to medical and dental care 8. Medical Home ✓ Regular care provider ✓ Minimum of one visit per year 9. Access to Supportive and Specialized Services ✓ Getting needed services ✓ Getting services in a timely manner	10. Self-Advocacy ✓ Likelihood of actively seeking information and asking questions about health, health care and quality of medical professionals

Information was collected for a total of eleven on-line populations (N=9400):

- Teenagers (age 13-17)
- A random sample of all adults, age 18 and over
- Adult populations for each of the following chronic conditions: Arthritis, Asthma, Coronary Artery Disease, Depression, Type II Diabetes, Hypertension
- Parents of Children with Asthma
- Caregivers of people who recently passed away
- Caregivers of people with Alzheimer's or other serious chronic conditions

The on-line sample was drawn from approximately one million individuals recruited to participate in an on-line survey panel (70% recruited via on-line sources, and 30% using random digit-dialing and mailed requests).

The on-line panel was stratified into groups according to age, gender, and education, based on U.S. Current Population Survey distributions (2000). Random samples were sequentially drawn from the one million person sample frame for purposes of survey administration. E-mail invitations and reminders were sent 3,000 at a time until target sample sizes were completed. Each invitation included a link to the online survey and a unique 5-digit access code that ensured that only one survey was taken from an individual computer, and that each invited participant only took the survey once. Only those respondents who completed at least 80% of the survey items were considered in the analyses.

A screening survey was first administered to identify individuals who qualified for one or more of the eleven specific surveys. A probabilistic process was used to assign individuals to one survey if they qualified for multiple versions, to ensure that the final respondent population for each target group (e.g., diabetes) represented the natural distribution of comorbidities in that population.

## **SURVEY RESPONDENTS**

- A screener questionnaire was sent by e-mail to a total of 110,574 individuals to determine their eligibility to participate in the chronic condition and caregiver population surveys. Based on information from the research firm contracted to collect the data, approximately 2.5% (n=2764) of the email addresses were not valid, resulting in a base of 107,810 individuals actually receiving our e-mailed screener. Of these, a total of 24,053 qualified to be surveyed.
- A total of 6,447 individuals completed the survey (27%). Table 2 provides a breakdown of individual samples.
- In order to have a dataset that is more reflective of the general US population, several datasets were weighted by age and sex within that condition using estimates from the

1998 National Health Interview Survey. The sample of caregiver parents to children with asthma was also weighted by race of the child, in addition to age and sex. The samples of caregivers to terminally ill and chronically ill patients were not weighted as no nationally representative standard data for such caregivers could be found.

- Panel composition and response rates by race did not provide adequate numbers of respondents for the general adult survey. A supplementary e-mail invitation was sent to all panel members residing in a random sample of selected U.S. zip codes known to include over 30% African-American or Hispanic surnamed residents. All respondents of all races who responded to the supplementary recruitment cycle were included in the analysis.

**Table 2: Response Rates for Each Chronic and Caregiver Survey 2001**

<b>Survey</b>	<b>Qualified</b>	<b>Completed</b> (80% of all questions)	<b>Completion Rate</b> (Completed/Started)
<i>Baseline: 24,053 invitations sent to qualified and screened individuals</i>			
<u>Chronic conditions:</u>			
• Arthritis	2823	425	15%
• Asthma	2571	443	17%
• Cardiovascular Disease	1555	421	27%
• Depression	4270	1217	29%
• Adult diabetes	1764	1048	59%
• Hypertension	4524	459	10%
<b>Total</b>	<b>17507</b>	<b>4013</b>	<b>23%</b>
<u>Caregivers:</u>			
• Chronically ill	2928	1005	34%
• End of Life Care	2603	999	38%
• Pediatric Asthma	1015	430	42%
<b>Total</b>	<b>6546</b>	<b>2434</b>	<b>37%</b>
<b>Grand Total</b>	<b>24,053</b>	<b>6447</b>	<b>27%</b>

## MEASURES

All measures were selected such that they were:

- Stable over time and between surveys
- Scientifically credible (items used were borrowed, or derived from such reputable sources as HEDIS, CAHPS, BRFSS)
- Comparable between this particular sample and sources of benchmark data to check the external validity of the sample.

Three types of measures were administered to each chronic population:

1. Items that were given to *all participants*, including those without a chronic condition (see Table 1 for a summary).
2. Items that were given to all participants *with a chronic condition*.
3. Items that were given only to a *specific chronic condition*. These items were based on the national treatment guidelines for each condition. All participants who reported having a particular chronic condition, with the exception of arthritis sufferers, had a portion of their questionnaire dedicated to treatment issues regarding their particular condition.

Measures were re-coded to create proportions along a 0-100 continuum for ease of reporting and to standardize all scores for comparability. Measures with multiple items were combined in one of three ways:

1. A mean score was computed and a cut-off point assigned, so that people who fell above the cut-off were assigned a score of '100'.
2. A certain number of positive responses were required, for example 3 out of 4, in order to qualify for a score of '100'.
3. Responses across all items had to be positive to score 100.

In addition, responses of "I don't know" or "Refuse to answer" were counted as missing data.



THE  
ROBERT WOOD  
JOHNSON  
FOUNDATION®

Route 1 and College Road East  
P.O. Box 2316  
Princeton, NJ 08543-2316  
[www.rwjf.org](http://www.rwjf.org)

**FACCT**  
FOUNDATION FOR ACCOUNTABILITY

1200 NW Naito Parkway  
Suite 470  
Portland, OR 97209  
[www.facct.org](http://www.facct.org)