Barriers to Health Care Access in the Patient Experience

Patient Experience Survey
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Introduction

About the Patient Experience Survey

PhRMA’s Patient Experience Survey (PES) is a new research initiative designed to explore the barriers patients face in accessing health care and prescription medicines. Launched in the wake of the coronavirus pandemic, which exposed many of the vulnerabilities of our health care system, the survey reports the lived experiences of 4,765 Americans, including 3,612 who rely on prescription medicines. The research aims to understand how patients engage with the health care system, uncover the real, practical challenges Americans face around access and affordability and identify solutions that could make a meaningful difference.

Barriers to Health Care Access in the Patient Experience is the first report of the PES. The robust quantitative data, coupled with secondary data and insights from think tanks, government and academia to illuminate findings, inform analysis that connects Americans’ real experiences to a policy agenda that addresses their needs and concerns. The benchmark survey findings are included within, and the data will be tracked over time.
Executive Summary

Barriers to Health Care Access in the Patient Experience unpacks some of the key challenges American patients face when it comes to accessing and affording their prescription medicines. The survey data and patient testimonials paint a picture of the health care experience in America today – a system made more vulnerable in the wake of the COVID-19 pandemic. While most Americans are satisfied with the health care they receive (76%) and their ease in accessing the care that they need (70%), the data show the system may not be working for the sickest and most vulnerable among us.

The survey finds 13% of Americans are forgoing needed care, have trouble paying medical bills, have out-of-pocket costs that are more than they can afford, have no savings to cover medical expenses and worry about accessing and paying for care. This insecurity in health care access disproportionately affects those reporting the poorest health, the disabled and patients suffering from the most serious health conditions.

The systemic challenges of access and affordability in American health care go beyond the uninsured. Three in ten Americans that have insurance still face a financial barrier to care, like having trouble paying medical bills or having out-of-pocket costs that are more than they can afford. The data reveal that health insurance benefit design – including out-of-pocket expenses not covered by insurance and utilization management practices – is contributing to health care access insecurity and may be leading to poor health outcomes and higher out-of-pocket costs.

Out-of-pocket costs may lead to medication non-adherence. As the use of deductibles and coinsurance continues to rise, Americans report difficulty affording their medicines, contributing to poor medication adherence and poor health outcomes. The survey finds that for almost a third of Americans, health care out-of-pocket costs are unworkable for their budget. These out-of-pocket costs are strongly correlated with prescription abandonment; 87% of patients who take a prescription drug and have any outstanding medical debt report one or more episodes of non-adherence in the past year. Prescription abandonment and non-adherence, in turn, costs the health care system hundreds of billions of dollars in avoidable health outcomes.

Health plan use of utilization management can create significant barriers – especially for the sick. The data show the utilization management tools insurers use, like prior authorization and step therapy, are associated with challenges with prescription medicine adherence. Patients with some of the most serious chronic diseases – autoimmune diseases (62%), allergies (52%) and diabetes (52%) – are also more likely to report experiences with utilization management than other Americans who take prescription medicines. In addition, the burdens of utilization management appear to disproportionately impact people of color. Black Americans (56%) and Hispanic Americans (60%) report being subject to utilization management practices, while only 36% of white Americans report experiencing the same.

Further complicating patients’ access to care is the COVID-19 pandemic. Four in ten (40%) Americans say the pandemic has made them more worried and anxious about their family’s ability to access care. In the wake of the pandemic and with access issues like high out-of-pocket costs and utilization management, it’s clear we need to build a more resilient system that has fewer barriers to care.

Patients with insurance coverage favor solutions that lower out-of-pocket costs (59%) compared with paying lower premiums each month (41%). Those experiencing the greatest anxiety about and most problems affording care, in particular, prioritize lowering out-of-pocket costs to reduce barriers to their health care (65%) over lowering premiums (35%).

By uncovering the everyday challenges American patients face, the report provides a roadmap for solutions policymakers should pursue – policies that address inequities in health care, lower patient out-of-pocket costs at the pharmacy counter and remove barriers to access.
I. Health Insurance Design Leads to Access and Affordability Issues

Rising Out-of-Pocket Expenses Are Unaffordable to Many

Many Americans have been exposed to high cost sharing due to an increased use of deductibles¹ and coinsurance² by their health plans. As these out-of-pocket costs continue to cause affordability challenges, patients are expressing concern. In this benchmark survey, 31% of Americans say their health care out-of-pocket costs are unworkable for their budget.

Out-of-pocket costs required by insurance can be problematic for patients.

Out-of-pocket costs can be a real issue for Americans who struggle to pay for health care costs or don’t have savings to cover big expenses. PES data show Americans spent an average of $1,568 out of pocket on health care in the past year. One in five (22%) Americans also report it’s difficult to afford the out-of-pocket expenses required by their health insurance. PES data also show that 44% have less than $1,000 in savings to pay for emergency or unforeseen expenses. Reporting by the Commonwealth Fund is consistent, noting that nearly half (46%) of Americans would not have the money to cover a $1,000 medical bill within 30 days in the case of an unexpected medical event.³

As a younger retiree on disability, I’ve seen my insurance costs skyrocket over the last several years to the tune of a $7,900 deductible. During that time, I have had to dip into my savings and retirement to pay for coverage.

— Richard K., Missouri

Out-of-Pocket Costs:
The amount individuals and families pay for health care bills and expenses, in addition to their monthly premium costs, that are not paid by health insurance plans.
Patients who are very worried about accessing and affording the care they need report significantly higher out-of-pocket costs. PES asked respondents how much they spend each month on out-of-pocket costs for all their health care needs, including doctors’ visits, prescription medicines, diagnostics and more. Patients with the greatest anxiety about and most problems affording care report a mean of $703/month, compared to the rest of the public who report $232/month.

Hospital bills cause the most financial strain and concern.

Americans report having the most problems paying their hospital bills, with 30% of those with problems paying medical bills in the past year indicating hospital bills were the largest share of their medical bills. Data further reveal that 24% of Americans would be “very worried” about their ability to pay for their hospital bills, followed by 19% very worried about paying for doctor bills and diagnostics. Sixteen percent of Americans reported they would be very worried about paying for prescription medicines.

Patients are increasingly exposed to cost sharing in the form of deductibles and coinsurance. Commonwealth Fund data find that the number of adults with deductibles of $1,000 per year or more has doubled in the last decade. They estimate that even before the COVID-19 pandemic, 43% of U.S. households were inadequately insured — meaning they were uninsured, were insured but had experienced a coverage gap in the past year or were insured continuously but had such high out-of-pocket costs relative to their income that they were effectively underinsured — resulting in out-of-pocket costs that equaled 10% or more of their household income in addition to their monthly spending on health insurance premiums.

Source: Commonwealth Fund
Thirteen percent of Americans are uniquely vulnerable in our health care system, driven by unaffordable out-of-pocket costs.

PES data show the health care system is not working for about 13% of Americans. These individuals experience the greatest anxiety about and most problems affording care - what we call health care access insecurity.

Having health insurance coverage is not always enough for Americans to be able to afford the care they need when they need it. The systemic challenges of access and affordability in American health care go beyond the uninsured. Three in ten Americans that have insurance still face a financial barrier to care, like having trouble paying medical bills or having out-of-pocket costs that are more than they can afford.

The study also finds that the Americans with the greatest anxiety about and most problems affording care are overwhelmingly those reporting the poorest health, the disabled and patients suffering from the most serious health conditions. Americans with chronic conditions such as infectious diseases (29%), mental health challenges (27%) and autoimmune diseases (24%) disproportionately experience health care access insecurity. Additionally, four in 10 (41%) small-town Americans report health care access insecurity.

The Sickest and Most Vulnerable Are More Likely To Experience Severe Health Care Access Insecurity

41% of Americans Who Take Prescription Medicines Report at Least One Episode of Non-Adherence in the Past Year.

This Includes:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skipped one or more doses</td>
<td>27%</td>
</tr>
<tr>
<td>Did not fill or pick up the medicine from the pharmacy</td>
<td>21%</td>
</tr>
<tr>
<td>Delayed picking up or taking the medicine</td>
<td>19%</td>
</tr>
<tr>
<td>Didn’t finish all of the medicine</td>
<td>17%</td>
</tr>
<tr>
<td>Cut your pills in half</td>
<td>16%</td>
</tr>
<tr>
<td>Picked up the medicine, but did not take any of the medicine</td>
<td>11%</td>
</tr>
</tbody>
</table>

Q: In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed?
Base: 3,612 Patients who take prescription medicines
Source: Patient Experience Survey, June 25 - July 9, 2021

Non-adherence:
Not taking medicines as prescribed, including skipping doses, not filling or picking up prescriptions at the pharmacy, cutting pills in half or not finishing medicine, among others.
Insurance Practices Can Lead to Non-Adherence

Non-adherence can negatively impact patients’ overall health and drive up health care costs for the system. PES data underscore widespread challenges with adherence, finding that 41% of patients who take a prescription medicine report at least one episode of non-adherence in the past year, including skipping doses, not filling or picking up prescriptions at the pharmacy, cutting pills in half or not finishing medicines as prescribed. More than one in four (27%) Americans who use prescription medicines report having skipped one or more doses in the past 12 months.

Out-of-pocket costs can impact adherence.

Health insurance plans play an outsized role in determining patients’ cost-sharing amounts through deductibles, copays or coinsurance and by determining which services and medicines are covered. Health insurance benefit design therefore has a direct and meaningful impact on prescription adherence or abandonment. More than half (52%) of patients taking prescription medicines with a high-deductible health plan report one or more episodes of non-adherence in the past year. Those who have accumulated medical debt are in turn the most likely to have challenges adhering to their medicines. PES data show approximately nine in 10 patients (87%) with medical debt experienced one or more episodes of non-adherence in the past year. Other public studies further underscore this impact, noting that very high out-of-pocket expenses may have dangerous consequences; high costs have been linked to poor medication adherence and treatment delays in patients with rheumatoid arthritis, kidney disease, diabetes, oral cancer and breast cancer.

Non-adherence often leads to adverse health outcomes.

Predictably, Americans who forego strict adherence to their prescription medicines face adverse health outcomes. Half (48%) of all those reporting one or more episodes of non-adherence say their health suffered consequently. That number increases to 82% of patients with an infectious disease who experienced non-adherence and report negative health consequences.

Patient Spotlight: Patients with Serious Health Conditions

Patients with some of the most serious health problems, like infectious diseases, mental health challenges, autoimmune diseases, diabetes and cancers, also tend to face the biggest challenges adhering to their medicines. Data shows that in the past 12 months, these patients experienced a disproportionate share of events related to medication non-adherence:

- 55% of patients with an infectious disease delayed picking up or taking their medicine, compared with just 19% of all patients taking a prescription medicine
- 50% of patients with an autoimmune disease skipped one or more doses, compared with 27% of all patients taking a prescription medicine

These patients are also more likely to be very worried about accessing and affording the care they need while experiencing utilization management practices.

Q: In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed?
Base: Variable subgroups of patients taking prescription medicines
Source: Patient Experience Survey, June 25 – July 9, 2021

Health Insurance Benefit Design:

The policies that determine health plan benefits, including how patients can access covered services and how much they pay, including through copays, coinsurance and deductibles.
Barriers to Health Care Access in the Patient Experience

Non-adherence often leads to increased health care costs.

PES data show 85% of patients whose health was negatively impacted by medication non-adherence had to seek additional health care resources. And certain patient groups experienced disproportionate impacts. For instance, 90% of patients with an infectious disease whose health was negatively impacted by medication non-adherence had to make another appointment with their doctor.

Research cited by the Centers for Disease Control and Prevention (CDC) underscores this impact, noting that hospital admission rates increase for non-adherent patients with chronic illness by up to 69%. The cost of additional, and avoidable, health care services as a result of non-adherence in the United States has been estimated at $100 billion to $300 billion annually — including the costs of avoidable hospitalizations, nursing home admissions and premature deaths.

Many Patients Report Their Health Suffered Because of an Episode of Non-Adherence

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients with an infectious disease</td>
<td>82%</td>
</tr>
<tr>
<td>Patients with an autoimmune disease</td>
<td>79%</td>
</tr>
<tr>
<td>Patients with diabetes</td>
<td>51%</td>
</tr>
<tr>
<td>All patients taking prescription medicines</td>
<td>48%</td>
</tr>
</tbody>
</table>

Q: Did your health suffer because of [Adherence issue]? [% Yes]  
Base: 1,324 Patients who encountered an episode of non-adherence in the past year  
Source: Patient Experience Survey, June 25 – July 9, 2021

Prior Authorization:

A health care professional must receive approval from the insurance company before the insurance company will cover the medicine.
Insurance Hurdles Deny or Limit Patient Access to Medicines

On top of health care affordability problems, PES data show health plan utilization management practices are creating significant barriers and furthering inequities.

In practice, health insurers use utilization management tools to determine when and how a patient can access a particular medicine, through methods such as prior authorization and step therapy. These additional barriers to accessing prescription medicines can result in delays, prevent patients from picking up their prescriptions or require patients to take an alternative medicine preferred by the insurance company.

Utilization management can have broad impacts on patients, including challenges with prescription medicine adherence.

Utilization management can contribute to medication adherence challenges.

The barriers imposed by utilization management can contribute to poor medication adherence or prescription abandonment. PES data show 82% of patients with one or more episode of non-adherence report that they were subject to some form of utilization management. Of those who were required to undergo step therapy, 57% abandoned a prescription medicine in the past year (that is, failed to fill or pick up a medicine that had been prescribed). A recent survey by the American Medical Association validates these data, finding 94% of physicians reported that prior authorization results in care delays and 79% may lead to treatment abandonment.¹

And the hurdles imposed by utilization management disproportionately affect patients who have the most concerns about accessing and affording their care. As a whole, seven in 10 (68%) of the Americans who are very worried about accessing and affording the care they need report utilization management barriers, compared with just 38% of the rest of the population. They are also more likely to report experiencing an adverse health impact as a result of utilization management than other patients (88% versus 59% of those who reported a utilization management barrier). These Americans already face greater barriers to health care access, and utilization management is making it even harder.

When I first learned of my breast cancer diagnosis, my oncologist immediately created my treatment plan. I was supposed to immediately begin treatment to slow/reduce the growth of the cancer. However, at first my insurance company refused to cover the medication and required me to get authorization before finally deciding to cover it. This entire process took two critical weeks to resolve.”

– Silvia A., Arizona

Eighty-two percent of Americans who report at least one episode of non-adherence report that they were subject to some form of utilization management.

Q: In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed?
Base: 1,324 Patients who encountered an adherence event in the past year
Source: Patient Experience Survey, June 25 – July 9, 2021

Step Therapy:
A patient is required to fail first on an alternative medicine preferred by the insurer before the originally prescribed medicine is covered.
Utilization management impacts some patient populations more severely.

The burdens of utilization management appear to disproportionately impact people of color and people with serious, chronic diseases.

- While majorities of Black Americans (56%) and Hispanic Americans (60%) report being subject to utilization management practices, only 36% of white Americans report experiencing the same.

- Patients with some of the most serious chronic diseases — autoimmune diseases (62%), allergies (52%) and diabetes (52%) — are more likely to report experiences with utilization management than other Americans who take prescription medicines.

- Parents, especially those with young children, are also disproportionately impacted by utilization management. Eighty percent of parents with newborns and 68% of parents with infants experienced utilization management for prescription medicines in the past year.

Q: Have any of the following happened to you or your family over the past three months? Please answer regarding any kind of prescription medicine for any condition or illness.

Base: 3,612 Patients who take prescription medicines
Source: Patient Experience Survey, June 25 – July 9, 2021

“...In my son’s case, after three years of being stable and controlled on his insulin, our insurer abruptly denied coverage and instead required him to try another type of insulin and have it fail first, before being permitted to go back to his originally prescribed insulin.”

— Liz P., New Jersey

“I have suffered from sleep issues for many years and have had several bouts with severe sleep deprivation. My doctor had me try several different medications to help, but nothing worked. Then he recommended a new prescription for an insomnia medication, and it actually worked! I switched insurance this year to a company that has my medication on their formulary, however, they still will not cover it or apply it to our deductible until I try other medications first for a period of time.”

— Darin L., Colorado
The access challenges outlined in the previous section have been exacerbated by the COVID-19 pandemic. For example:

- Four in ten Americans say the pandemic has made them more worried and anxious about their family’s ability to access care.
- One in five (23%) Americans reports being unable to access the health care they needed over the past three months.
- Similar percentages note having experienced anxiety over their ability to access health care (23%) and difficulty paying for medical expenses (21%).

A Gallup-West U.S. Health Care Study also found that 40% of U.S. adults are concerned about paying for their cost of care if diagnosed with COVID-19 – with significant differences between white Americans and Americans of color. More than half (58%) of adults of color vs. 32% of white adults report that they are either “extremely concerned” or “concerned.”

These findings suggest more needs to be done to ensure a more resilient, affordable and equitable health care system.
COVID-19’s Impact on Those Facing the Greatest Challenges Accessing and Affording Health Care

PES data show that the pandemic has exacerbated anxiety around health care access for millions of Americans - especially those who have the most difficulty affording the care they need. The pandemic has made 40% of Americans more worried and anxious about their family’s ability to access health care. And the effect on the most vulnerable is disproportionate. Among those experiencing health care access insecurity, 73% say the pandemic has made them even more worried about accessing needed care.

Similarly, The Commonwealth Fund also finds that the COVID-19 pandemic has brought about financial instability for many Americans. For example, nearly half of Americans reported being directly affected by the pandemic in at least one of three ways:

- Getting COVID-19
- Losing income
- Losing employer-sponsored health insurance coverage

"The pandemic created challenges that my family never imagined we’d have to face. As someone who works with newborns at a hospital, I saw the similar worries from parents for their babies.”

– Maggie M., Minnesota
PES and third-party data show the challenges related to health care access and affordability are largely driven by deteriorating health insurance coverage. Simply having insurance does not solve access and affordability issues - 10% of insured Americans report being unable to access and afford care, experiencing anxiety over their care and facing significant financial barriers.

As such, the policy solutions that Americans value tend to focus on demystifying their coverage - promoting transparency and predictability of their coverage - and lowering their out-of-pocket costs.

When asked about improving health care access for themselves and their families, Americans favor the following solutions:

- Reducing the burden of deductibles by requiring more items and services to be covered before the deductible kicks in (32% ranked it as their first or second choice);
- Limiting out-of-pocket costs (for instance, total costs not to exceed a certain percentage of household income) (31%);
- Requiring insurers to cover more medicines (30%);
- More transparency with costs (for instance, easy to find and understand cost estimates before treatment is received) (25%); and
- More predictability with out-of-pocket costs (for instance, fixed co-pays rather than coinsurance) (21%).

When exploring which expenses are most meaningful to address, Americans prioritize lowering their out-of-pocket costs, such as co-pays, coinsurance and deductibles, versus lowering their health insurance premiums.

- A majority of adults with insurance coverage prefer paying lower out-of-pocket costs (59%) compared with paying lower premiums each month (41%).
- Patients with serious diseases - especially those managing multiple conditions - are more likely to support coverage reform that addresses out-of-pocket costs.
- Those experiencing the greatest anxiety about and most problems affording care prioritize lowering out-of-pocket costs to reduce barriers to their health care (65%) over lowering premiums (35%).
Specific to prescription medicine coverage, two-thirds (66%) of Americans believe it is more important to pay lower out-of-pocket costs for medicines versus paying a lower premium each month. This support is consistent across patient, socioeconomic and partisan groups. The preference for lower out-of-pocket costs is more pronounced among certain groups that may face greater health disparities. This includes those with disabilities (77% prefer lowering out-of-pocket costs versus premiums), those managing multiple chronic conditions (74%), those with a household income between $10,000 and $49,000 per year (71%), those who identify as LGBTQ+ (71%), and Americans living in rural areas (70%).

In 2018 I was diagnosed with an aggressive form of blood cancer, and as a wife with 3 young daughters this was quite a shock. That shock continued when my insurance plan’s deductible for just one month’s treatment was $4,000 out-of-pocket. Reducing the burden of my deductible by requiring more services to be covered before it kicks in, or at least limiting my out-of-pocket costs, certainly would be a great help to both myself and others who are grappling with serious illness.”

—Shannon B., New York
Conclusion

As policymakers consider solutions to address access, affordability and equity, it is important to look at the entire health care landscape and the patient experience.

PES data and patient testimonials show that insurance coverage alone does not provide the needed support to enable accessible, affordable care for the most vulnerable. In fact, systemic elements such as high and/or unpredictable cost sharing and utilization management practices provide significant barriers. And overall out-of-pocket costs – not just those related to prescription medicines – compound the issue of affordability. These challenges have been further exacerbated by the COVID-19 pandemic.

All of this underscores the importance of patient-centered solutions that promote transparency, predictability and addressing coverage-related out-of-pocket costs. We need to look more broadly at the health care system, versus any one element, to improve health care for those with the greatest challenges accessing care.
Appendix

About the Author

The Pharmaceutical Research and Manufacturers of America (PhRMA) represents the country’s leading innovative biopharmaceutical research companies, which are devoted to discovering and developing medicines that enable patients to live longer, healthier and more productive lives. Since 2000, PhRMA member companies have invested more than $1 trillion in the search for new treatments and cures, including $91.1 billion in 2020 alone.

Methodology

PES was designed to collect robust and reliable data on the perceptions and behaviors of patients around access to health care generally, and prescription medicines specifically. A literature review was conducted around existing and relevant academic surveys, which helped to inform the questionnaire design. The questionnaire was tested and refined through a series of cognitive pre-tests and in-depth interviews to ensure measurement validity and reliability. The questionnaire was translated and cross-translated into Spanish for administration with Spanish-speaking households.

The survey was administered online among a sample of one of the largest general public and patient research panels – Dynata. The survey population was defined as all adults in the United States at least 18 years of age. However, the study was also designed to understand specific populations of interest, especially vulnerable populations (BIPOC, LGBTQX, lower SES groups) and patients suffering from chronic and other serious health conditions. Instead of sampling these groups separately (disproportionate to their incidence in the overall population), the overall sample size was adjusted to ensure a minimum sample size of key populations.

The sample was administered by applying quotas around key demographic variables, and the final data were weighted applying a post-stratification, RIM weighting methodology across nine demographic variables applying the latest Census data.

The survey was conducted between June 25 and July 9, 2021, with a final sample size of n=4,765 Americans, including n=3,612 patients taking prescription medicines.

Health Care Access Insecurity

PES explored various dimensions of how patients assess their experience accessing health care. We analyzed the data across multiple metrics and identified three core dimensions: (1) recent experience in accessing/affording care, (2) anxiety over access, and (3) financial barriers. We classified Health Care Access Insecure patients as those that report access challenges on all three dimensions. The table below shows how it is measured across seven separate metrics.

<table>
<thead>
<tr>
<th>Health Care Access Insecurity Index</th>
<th>All Americans</th>
<th>Insured Americans</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EXPERIENCE (unable to access/afford health care)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt needed health care but didn’t get it in the past 3 months.</td>
<td>22%</td>
<td>31% 29%</td>
</tr>
<tr>
<td>Household had problems paying for medical bills and expenses during the last 12 months.</td>
<td>21%</td>
<td></td>
</tr>
<tr>
<td><strong>ANXIETY (over ability to access/afford health care)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reported being very or somewhat worried about ability to access health care over the past three months.</td>
<td>22%</td>
<td>32% 29%</td>
</tr>
<tr>
<td>Reported being very worried about being unable to pay medical expenses if got sick or had an accident.</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td><strong>FINANCIAL BARRIER</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very or somewhat difficult to afford the out-of-pocket expenses not covered by health insurance.</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>No savings that could be accessed immediately to pay for emergency or unforeseen expenses.</td>
<td>19%</td>
<td>34% 29%</td>
</tr>
<tr>
<td>Reported spending more in out-of-pocket expenses than could afford last month.</td>
<td>26%</td>
<td></td>
</tr>
</tbody>
</table>
Endnotes


