

## Poor Treatment by Health Care Providers and Staff Is More Common among Vulnerable Populations

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### At a Glance

- In March 2016, nearly 1 in 10 adults reported being judged unfairly or treated with disrespect by a provider or its staff in the past 12 months.
- Poor treatment was more commonly reported by adults with certain protected characteristics, including adults with disabilities; lesbian, gay, bisexual, and transgender adults; Hispanic adults; and women.
- Over two-thirds of those experiencing poor treatment had a disruption in care as a result, including changing providers, delaying or forgoing needed care, or not following the provider's recommendations.

Several studies have shown that many vulnerable populations, including adults with disabilities, racial and ethnic minorities, sexual minorities, and low-income adults, report difficulties obtaining needed care (Agency for Health Care Research and Quality 2016; Centers for Disease Control and Prevention 2013; Iezzoni, Frakt, and Pizer 2011; Karpman and Long 2015; Shartzter, Long, and Anderson 2015; Skopec and Long 2015), and that certain populations may face discrimination in the provision of health care services (Institute of Medicine 2002; Lambda Legal 2010). The US Department of Health and Human Services recently published final regulations implementing section 1557 of the Affordable Care Act; those regulations protect certain vulnerable groups against discrimination in health care activities and programs established or funded by the federal government,<sup>1</sup> in part to promote equity in the health care system.<sup>2</sup> This paper reports on poor treatment by health care providers and staff among adults who would be protected under the new rule<sup>3</sup> and the effects of that treatment on their access to care.

### Data and Methods

We use data from the March 2016 wave of the Health Reform Monitoring Survey (HRMS), a probability-based Internet survey that has been conducted since 2013. The HRMS is based on cross-sectional samples of about 7,500 nonelderly adults (ages 18 to 64) per survey period; the sample is drawn from GfK's KnowledgePanel. Each round of the HRMS is weighted to be nationally representative.

The March 2016 HRMS included questions addressing poor treatment by providers or their staff and the perceived reasons for that poor treatment, based on questions from the Consumer Assessments of Healthcare Providers and Systems survey (Agency for Healthcare Research and Quality 2012). Those questions ask whether respondents felt that they had been judged unfairly or treated with disrespect by a doctor, other health care provider, or the provider's staff over the past 12 months. Those who responded that they had been judged unfairly or treated with disrespect were

asked, from among the following, their perceived reason or reasons for that poor treatment: the type of health insurance coverage you had, a lack of health insurance coverage, your race or ethnicity, your nationality, your age, your gender, your sexual orientation or gender identity, your personal or religious beliefs, your ability to speak English, a disability, a health condition, or other. Overall, 12.0 percent of respondents did not identify a specific reason for the poor treatment.

The March 2016 HRMS also included a follow-up question asking those who reported that they had been judged unfairly or treated with disrespect about the consequences of that treatment. Respondents were asked to choose all that applied from among the following: you changed providers; you delayed getting care you needed; you didn't get care you needed; you filed a complaint; you didn't follow the doctor or provider's recommendations; and other. For both questions, those responding "other" were able to enter their response into a text field. Overall, 16.5 percent of respondents did not identify a consequence of the poor treatment.

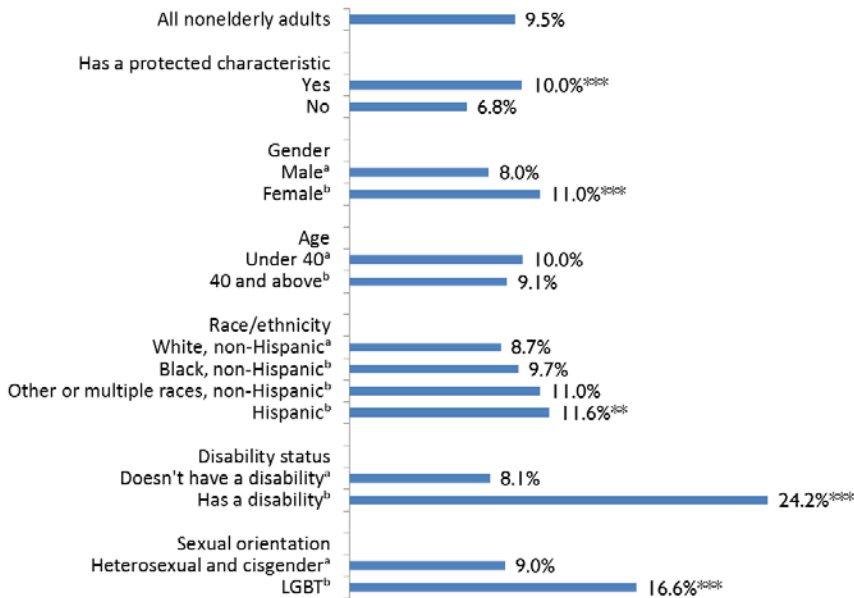
Throughout this brief, the term "protected characteristics" refers to the personal characteristics covered by the Department of Health and Human Services nondiscrimination regulation under the Affordable Care Act, including women, adults age 40 and above, racial and ethnic minorities, lesbian, gay, bisexual, and transgender (LGBT) adults, and adults with disabilities.<sup>4</sup> Overall, 87.0 percent of adults in our sample had at least one protected characteristic in March 2016 (data not shown).

Although the overall sample size of the March 2016 HRMS is 7,520, the sample sizes for some of the population groups with the protected characteristics examined here are relatively small (e.g., 465 for LGBT), making estimates for smaller minority groups relatively imprecise.

## Results

Overall, nearly 1 in 10 nonelderly adults (9.5 percent) reported being judged unfairly or treated with disrespect by a provider or its staff over the past 12 months in March 2016 (figure 1). Adults who had a protected characteristic were more likely to report such treatment than those who did not (10.0 percent versus 6.8 percent, respectively), and poor treatment was reported most frequently among adults with disabilities (24.2 percent), LGBT adults (16.6 percent), Hispanic adults (11.6 percent), and women (11.0 percent).

**Figure 1. Share of Nonelderly Adults Judged Unfairly or Treated with Disrespect by a Provider or Its Staff over the Past 12 Months, by Protected Characteristic**



Source: Authors' analysis of the March 2016 Health Reform Monitoring Survey.

Notes: LGBT is lesbian, gay, bisexual, and transgender. Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375). For simplicity, we use the age discrimination standard of age 40 and over from the Age Discrimination in Employment Act of 1967, 29 USC 621. The sample size is 7,520 nonelderly adults.

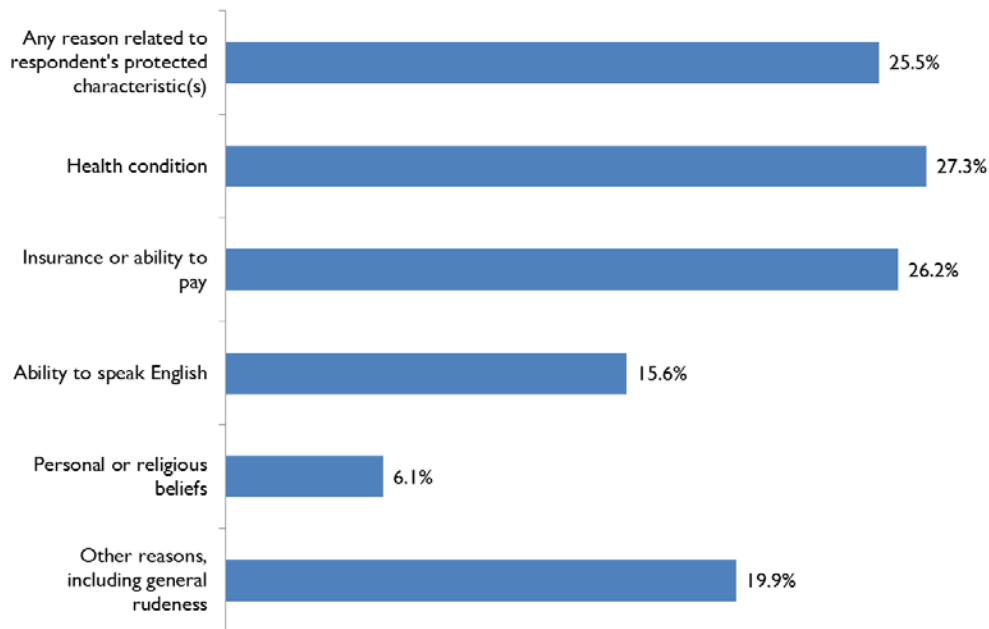
<sup>a</sup> Reference group

<sup>b</sup> Protected characteristics

\*\*\* Estimate differs significantly from estimate for the reference group at the 0.1/0.05/0.01 percent levels, using two-tailed tests.

When asked the perceived reason for being judged unfairly or treated with disrespect by a provider or its staff, most adults did not identify their protected characteristic as the reason (figure 2). Among those who reported poor treatment, only 25.5 percent attributed the treatment to one or more of their protected characteristics (figure 3). Beyond protected characteristics, the most common reasons given for being judged unfairly or treated with disrespect among adults who had at least one protected characteristic were having a health condition (27.3 percent)—though some health conditions are protected by the prohibition on discrimination because of disability—and economic factors, including income, no insurance coverage, or type of insurance coverage (26.2 percent). In addition, 19.9 percent of those who reported poor treatment selected “other” as the reason for the poor treatment, with many using the text field to indicate that the treatment was not “personal” because the provider was generally rude or seemed rushed.

**Figure 2. Perceived Reasons for Poor Treatment by Providers or Its Staff, among Those with a Protected Characteristic Reporting Poor Treatment**

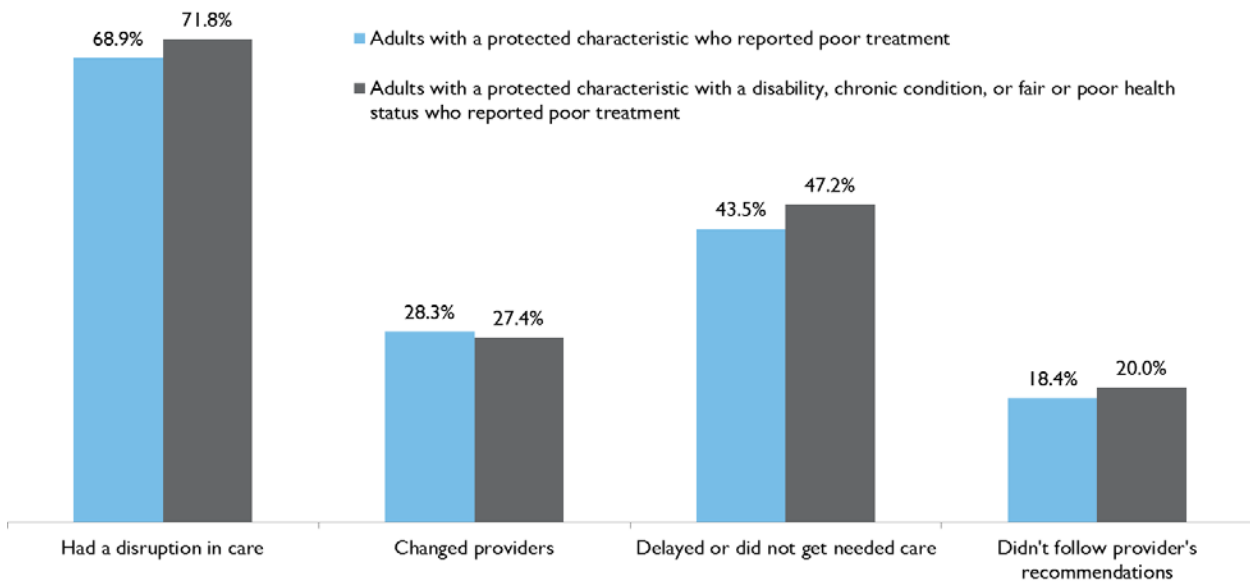


Source: Authors' analysis of the March 2016 Health Reform Monitoring Survey.

Notes: Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375). For simplicity, we use the age discrimination standard of age 40 and above from the Age Discrimination in Employment Act of 1967, 29 USC 621. All estimates above include only those respondents who had at least one protected characteristic. Respondents were asked to select all responses that applied. Sample size is 636 nonelderly adults.

Among adults with a protected characteristic, those who reported poor treatment were nearly three times as likely as those who did not report poor treatment to have a disability (24.3 percent versus 8.4 percent), more than twice as likely to report fair or poor health (29.2 percent versus 13.6 percent), and more likely to report a chronic condition (39.5 percent versus 29.6 percent), highlighting the challenges faced by those with health issues (table 1). Adults reporting poor treatment were also much more likely to have family income at or below 138 percent of the federal poverty level (41.8 percent versus 28.0 percent) and to have public insurance coverage (34.5 percent versus 18.4 percent), raising concerns about poor treatment by providers and staff compounding financial barriers to care. Beyond those factors, adults reporting poor treatment were also more likely than were those who did not report poor treatment to be less educated, to be female, and to be LGBT.

**Figure 3. Consequences of Being Judged Unfairly or Treated with Disrespect by Providers or Staff over the Past 12 Months among Adults with a Protected Characteristic Reporting Poor Treatment, by Health Conditions**



Source: Authors' analysis of the March 2016 Health Reform Monitoring Survey.

Notes: Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375). For simplicity, we use the age discrimination standard of age 40 and above from the Age Discrimination in Employment Act of 1967, 29 USC 621. Respondents were asked to select all responses that applied. The measure "had a disruption in care" is the total of the three other measures. Sample size is 636 nonelderly adults with a protected characteristic and 391 adults with a disability, chronic condition, or fair or poor health status who had a protected characteristic. All estimates include only those respondents who reported being judged unfairly or treated with disrespect by a provider or its staff in the past 12 months.

**Table 1. Comparison of Nonelderly Adults with a Protected Characteristic Who Were and Were Not Judged Unfairly or Treated with Disrespect by a Provider or Staff in the Past 12 Months**

	Adults who reported negative experience in the past 12 months	Adults who didn't report negative experience in the past 12 months
<b>Protected characteristics</b>		
Female	64.6%	57.8%***
Age 40 and over	55.8%	61.6%**
Not white or Hispanic	47.6%	43.3%*
Has a disability	24.3%	8.4%***
LGBT	12.7%	7.0%***
<b>Other characteristics</b>		
<b>Demographic characteristics</b>		
Married or partnered	53.1%	60.6%***
US citizen	88.4%	89.2%
<b>Socioeconomic characteristics</b>		
<i>Education</i>		
Less than high school	14.9%	11.7%*
High school or some college	59.0%	58.1%
College	26.1%	30.2%**
<i>Family income</i>		
Less than or equal to 138% of FPL	41.8%	28.0%***
Greater than 138% but less than 400% of FPL	34.7%	34.9%

At or above 400% of FPL	23.5%	37.1%***
<i>Health insurance coverage</i>		
Private coverage	55.6%	71.5%***
Public coverage	34.5%	18.4%***
Uninsured	9.9%	10.1%
<b>Health</b>		
<i>Self-reported health status</i>		
Excellent or very good	33.6%	49.9%***
Good	37.0%	36.3%
Fair or poor	29.2%	13.6%***
Has a chronic condition	39.5%	29.6%***
Has a disability, a chronic condition, or is in fair or poor health	58.5%	38.6%***
Sample size	636	6,046

Source: Authors' analysis of the March 2016 Health Reform Monitoring Survey.

Notes: FPL is federal poverty level; LGBT is lesbian, gay, bisexual, and transgender. Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375). For simplicity, we use the age discrimination standard of age 40 and above from the Age Discrimination in Employment Act of 1967, 29 USC 621. All estimates above include only those respondents who had at least one protected characteristic. Chronic conditions are asthma; breathing problems; chronic obstructive pulmonary disease; diabetes; epilepsy; heart disease, heart attack, or other heart condition; and hypertension.

\*/\*\*/\*\* Estimate differs significantly from estimate for those reporting negative treatment at the 0.1/0.05/0.01 levels, using two-tailed tests.

When asked about the consequences of the poor treatment they had experienced, 28.3 percent of the adults with a protected characteristic reported that they changed providers, 18.4 percent reported that they did not follow their provider's recommendations, and 43.5 percent reported that they delayed or did not get needed care (figure 3). Despite the negative experiences, only 18.9 percent of the adults who reported that the poor treatment was because of a protected characteristic reported filing a complaint (data not shown). Overall, 68.9 percent of those reporting poor treatment experienced a disruption in care as a result of that treatment, which we define as changing providers, not following providers' recommendations, or delaying or not getting needed care.<sup>5</sup>

Among those reporting poor treatment who had a disability, chronic condition, or fair or poor health status, nearly three-quarters (71.8 percent) reported changing providers, ignoring provider recommendations, or delaying or forgoing needed care, raising concerns about continuity of care for these vulnerable adults (figure 3).

## Conclusion

Although most adults did not report being judged unfairly or treated with disrespect by a health care provider or its staff over the past 12 months, those who did report such treatment were more likely to be members of vulnerable populations, including adults with certain protected characteristics (adults with disabilities, LGBT adults, Hispanic adults, and women) and lower-income groups (those with family incomes at or below 138 percent of the FPL and those covered by public insurance). More than half of those reporting poor treatment had a disability, had a chronic condition, or reported fair or poor health.

Among the adults reporting negative treatment by health care providers or staff, more than two-thirds reported a disruption in care as a result of the negative experience. Several studies have

shown that many vulnerable populations report diminished access to care (Agency for Health Care Research and Quality 2016; Centers for Disease Control and Prevention 2013; Iezzoni, Frakt, and Pizer 2011; Karpman and Long 2015; Shartzler, Long, and Anderson 2015; Skopec and Long 2015), and our findings suggest that negative experiences with providers and their staff may exacerbate these difficulties. In particular, among adults with disabilities, chronic conditions, or fair or poor health status who reported a negative experience, almost three-quarters reported a disruption in care as a result of the treatment, potentially placing these high-need groups at risk of poor health outcomes.

Although the new US Department of Health and Human Services nondiscrimination rules provide additional protection against discrimination in health care programs based on protected characteristics, including sexual orientation and gender identity, most of those reporting negative experiences did not identify a protected characteristic as the perceived reason for negative treatment. If those perceptions are correct, the new regulations will address only some of the barriers faced by vulnerable adults. In particular, those who feel they were treated unfairly or with disrespect because of their income or their having public coverage—a finding that has been noted in other contexts<sup>6</sup>—will not have any additional recourse under the regulations.

In addition, less than one in five of those reporting a negative experience related to their protected characteristics also reported filing a complaint as a result of the negative experience. It remains to be seen whether implementation of the US Department of Health and Human Services nondiscrimination rules will increase awareness of protected status among both patients and providers, leading to fewer negative experiences and, when negative experiences based on protected characteristics do occur, an increase in the filing of complaints by patients. Targeted education on the nondiscrimination rules for adults with disabilities or other health problems and their providers may be warranted given those populations' high rates of reporting poor treatment and consequent disruptions in care.

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## About the Series

This brief is part of a series drawing on the Health Reform Monitoring Survey (HRMS), a quarterly survey of the nonelderly population that is exploring the value of cutting-edge Internet-based survey methods to monitor the Affordable Care Act (ACA) before data from federal government surveys are available. The briefs provide information on health insurance coverage, access to and use of health care, health care affordability, and self-reported health status, as well as timely data on important implementation issues under the ACA. Funding for the core HRMS is provided by the Robert Wood Johnson Foundation, the Ford Foundation, and the Urban Institute.

For more information on the HRMS and for other briefs in this series, visit [www.urban.org/hrms](http://www.urban.org/hrms).

## About the Authors

Laura Skopec is a research associate and Sharon K. Long is a senior fellow with the Urban Institute’s Health Policy Center. The authors gratefully acknowledge the suggestions of Stephen Zuckerman.

## Notes

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<sup>1</sup> 81 FR 31375.

<sup>2</sup> US Department of Health and Human Services, “HHS Finalizes Rule to Improve Health Equity under the Affordable Care Act,” press release, May 13, 2016.

<sup>3</sup> Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375) and include women, adults age 40 and above, racial and ethnic minorities, LGBT adults, and adults with disabilities. For simplicity, we use the age discrimination standard of age 40 and above from the Age Discrimination in Employment Act of 1967, 29 USC 621.

<sup>4</sup> Protected characteristics are based on the US Department of Health and Human Services nondiscrimination rule (81 FR 31375) and include women, adults age 40 and above, racial and ethnic minorities, LGBT adults, and adults with disabilities. For simplicity, we use the age discrimination standard of age 40 and above from the Age Discrimination in Employment Act of 1967, 29 USC 621.

<sup>5</sup> This includes those reporting changing providers, not following the provider’s recommendations, a delay in care, and an unmet need for care. Respondents were able to choose all consequences that applied, so the estimates shown in figure 3 cannot be added together to arrive at this estimate.

<sup>6</sup> Chris C. Duke and Christine Stanik, “Overcoming Lower-Income Patients’ Concerns about Trust and Respect from Providers,” *Health Affairs Blog*, August 11, 2016.