

**UNITED STATES DISTRICT COURT  
FOR THE SOUTHERN DISTRICT OF NEW YORK**

STATE OF NEW YORK *et al.*,

*Plaintiffs,*

v.

UNITED STATES DEPARTMENT OF  
HEALTH AND HUMAN SERVICES *et*  
*al.*,

*Defendants.*

Civil Action No. 1:20-cv-05583-AKH

**BRIEF FOR AMICI CURIAE AMERICAN CANCER SOCIETY, AMERICAN  
CANCER SOCIETY CANCER ACTION NETWORK, AMERICAN HEART  
ASSOCIATION, AMERICAN LUNG ASSOCIATION, CANCER SUPPORT  
COMMUNITY, CANCERCARE, CYSTIC FIBROSIS FOUNDATION,  
EPILEPSY FOUNDATION, HEMOPHILIA FEDERATION OF AMERICA,  
NATIONAL COALITION FOR CANCER SURVIVORSHIP, NATIONAL  
MULTIPLE SCLEROSIS SOCIETY, NATIONAL ORGANIZATION FOR  
RARE DISORDERS, NATIONAL PATIENT ADVOCATE FOUNDATION,  
THE AIDS INSTITUTE, AND WOMENHEART: THE NATIONAL  
COALITION FOR WOMEN WITH HEART DISEASE IN SUPPORT OF  
PLAINTIFFS' RENEWED MOTION FOR SUMMARY JUDGMENT**

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## INTEREST OF AMICI CURIAE<sup>1</sup>

American Cancer Society (ACS), American Cancer Society Cancer Action Network (ACS CAN), American Heart Association (AHA), American Lung Association (ALA), Cancer Support Community (CSC), CancerCare, Cystic Fibrosis Foundation (CFF), Epilepsy Foundation, Hemophilia Federation of America (HFA), National Coalition for Cancer Survivorship (NCCS), National Multiple Sclerosis Society (NMSS), National Organization for Rare Disorders (NORD), National Patient Advocate Foundation (NPAF), The AIDS Institute, and WomenHeart: The National Coalition for Women with Heart Disease (WomenHeart) (collectively, Amici) represent millions of patients and consumers across the country facing serious, acute, and chronic health conditions. Amici have a unique perspective on what individuals and families need to prevent disease, manage health, and cure illness—and a deep understanding of the harm that will result if the 2020 Rule is left in place.

ACS's mission is to save lives, celebrate lives, and lead the fight for a world without cancer. ACS CAN is the nonpartisan advocacy affiliate of ACS, working

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<sup>1</sup> No counsel for a party authored this brief in whole or in part, and no party or counsel for a party made a monetary contribution intended to fund its preparation or submission. No person other than amici curiae or their counsel made a monetary contribution to the preparation or submission of this brief.

to reduce the burden of cancer across all communities, and striving for health equity nationwide.

AHA is the nation's oldest and largest voluntary organization dedicated to fighting heart disease and stroke and represents more than 40 million volunteers and supporters. As a direct result of the 2020 rule, those individuals that AHA represents will face discrimination or the threat of discrimination based on sex stereotyping and gender identity, therefore lowering the quality of medical care they receive and leading to worse health outcomes, especially as it pertains to cardiovascular health.

ALA is the nation's oldest voluntary health organization, representing the 36.6 million Americans with lung disease in all 50 states and the District of Columbia. Because all people with or at risk for lung cancer and lung diseases—such as asthma, Chronic Obstructive Pulmonary Disease (COPD) and pulmonary fibrosis—need access to quality health care to prevent or treat their disease, ALA strongly supports increasing health equity nationwide.

The CSC is the largest nonprofit provider of social and emotional support services for people impacted by cancer, providing \$50 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally.

CancerCare is the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer.

The CFF's mission is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care. The CFF advocates for policies that promote access to affordable, adequate health care for all people with cystic fibrosis.

The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of more than 3.4 million Americans with epilepsy and seizures. Uncontrolled seizures can lead to disability, injury, and even death. Epilepsy medications are the most common and most cost-effective treatment for controlling and/or reducing seizures—making timely access to quality, affordable, physician-directed and person-centered care and effective coverage for epilepsy medications vital for all people living with the epilepsies.

HFA is a community-based, grassroots advocacy organization that assists, educates, and advocates for people with hemophilia, von Willebrand disease, and other rare bleeding disorders. HFA works for patient access to quality and affordable care and coverage—priorities that reflect the nature of bleeding disorders as serious, life-long, and expensive health conditions.

NCCS was founded by and for cancer survivors and advocates for quality cancer care for all people touched by cancer. NCCS opposed any effort to restrict access to health care, particularly for vulnerable populations.

The NMSS mobilizes people and resources so that everyone affected by multiple sclerosis (MS) can live their best lives, while also seeking to end MS forever. To fulfill this mission, the NMSS funds more MS research and provides more programs for people with MS and their families than any other voluntary health organization in the world. The NMSS works to ensure that all people with MS have access to affordable high-quality health care.

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

NPAF is dedicated to elevating patient and caregiver voices as part of improving equitable access to affordable quality care, particularly for our most underserved populations. NPAF is the advocacy affiliate of Patient Advocate Foundation (PAF), a national organization that provides direct assistance to families coping with complex and chronic health conditions to help meet their most pressing needs for financial and social services advocacy and support.

The AIDS Institute is a nonpartisan, nonprofit organization dedicated to ensuring that all people living with, or at risk of, HIV, viral hepatitis, and other chronic illnesses have access to the care and services they need.

WomenHeart is a national patient-centered organization that supports, educates and advocates for women living with and at risk of heart disease. Women sometimes face sexism and discrimination in the health care system; WomenHeart works to ensure that all people are treated fairly and without bias when seeking health care.

Amici are all deeply concerned about the effect the 2020 Rule will have on the individuals and families they represent. As a direct result of the rule, many individuals will face discrimination or the threat of discrimination, which will delay access to timely treatment, lower the quality of medical care, and result in poorer health outcomes. Amici submit this brief to assist the Court in understanding the nature and extent of this harm.

## **INTRODUCTION**

Discrimination on the basis of sex, gender identity, transgender status, sexual orientation, national origin, language proficiency, and similar characteristics has no place in our health care system. Such discrimination can be particularly harmful for people suffering from chronic conditions, who often must rely on health care providers and insurance for access to lifesaving treatments. Indeed,

despite progress in treating chronic diseases like cancer or multiple sclerosis, not all groups are benefitting from that progress. Discrimination of all kinds continues to contribute to disparate outcomes from chronic diseases. Eliminating discrimination and the resulting barriers to care is critical for achieving better health outcomes for the millions of patients and consumers Amici represent.

Congress agrees. It adopted section 1557 to protect individuals from discrimination and to avoid the costs that follow when such discrimination happens. But the 2020 Rule undermines section 1557 by arbitrarily and capriciously rolling back protections for lesbian, gay, bisexual, transgender, and queer (LGBTQ) people and limited-English-proficient individuals. Amici thus join plaintiffs in asking the Court to declare the 2020 Rule unlawful and enjoin its enforcement.

## ARGUMENT

### **I. NONDISCRIMINATION IN HEALTH CARE AND INSURANCE IS CRITICAL FOR LGBTQ INDIVIDUALS WITH CHRONIC DISEASES**

#### **A. LGBTQ People With Chronic Diseases Face Distinct Challenges Because Of Discrimination**

Nearly everyone will require health care at some point in their lives. *See Nat'l Fed. of Indep. Bus. v. Sebelius*, 567 U.S. 519, 547 (2012). That fact is apparent from looking at even just a subset of the diseases on which Amici focus:

- More than 1.8 million new cancer cases are expected to be diagnosed in the United States in 2020, while more than 16.9 million Americans are living with a history of cancer. Am. Cancer Soc’y, *Cancer Facts & Figures 2020*, at 1.<sup>2</sup>
- Roughly four out of ten Americans will develop cancer in their lifetimes. *Id.* at 2.
- An additional 121.5 million American adults are living with cardiovascular diseases, while 45.1% of Americans are projected to have some form of cardiovascular disease by 2035. Salim S. Virani et al., *Heart Disease and Stroke Statistics—2020 Update*, Am. Heart Ass’n (2020).<sup>3</sup>
- The lifetime risk for developing cardiovascular disease in those free of known disease at age 45 is almost two in three for men and greater than one in two for women. John T. Wilkins et al., *Lifetime Risk and Years Lived Free of Total Cardiovascular Disease*, 308 J. AM. MED. ASS’N 1795, 1798 (2012).
- Another 54 million Americans have arthritis; 36.6 million have some form of chronic lung disease; and 23.5 million suffer from autoimmune diseases, including nearly one million with multiple sclerosis (MS). Ctrs. for Disease Control & Prevention, *Improving the Quality of Life for People With Arthritis*<sup>4</sup>, Ctrs. for Disease Control & Prevention, *2017 National Health Interview Survey* (2018) (analysis by ALA Epidemiology and Statistics Unit using SPSS Software); Nat’l Multiple Sclerosis Soc’y, *MS Prevalence*<sup>5</sup>; Nat’l Inst. of Env’t Health Scis., *Autoimmune Diseases*.<sup>6</sup>

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<sup>2</sup> <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf>.

<sup>3</sup> <https://www.ahajournals.org/doi/pdf/10.1161/CIR.0000000000000757>.

<sup>4</sup> <https://www.cdc.gov/chronicdisease/resources/publications/aag/arthritis.htm>.

<sup>5</sup> <https://www.nationalmssociety.org/About-the-Society/MS-Prevalence>.

<sup>6</sup> <https://www.niehs.nih.gov/health/topics/conditions/autoimmune/index.cfm>.

- Nearly one in five adults in the United States lives with a mental illness. Nat'l Inst. of Mental Health, *Statistics*.<sup>7</sup>
- Approximately 1.2 million Americans are living with HIV, a disease that requires lifetime medical care. Ctrs. for Disease Control & Prevention, *HIV Surveillance Supplemental Report 2020 25:1* (2020) (Table 7).<sup>8</sup>
- According to the National Institutes of Health, 1 in 10 people are affected by a rare disease, and half of all people diagnosed with a rare disease are children. Nat'l Insts. of Health, *Advancing Research on Rare Diseases* at 1 (Feb. 2020).<sup>9</sup>

The population of people with these chronic diseases includes many who identify as LGBTQ. Am. Cancer Soc'y, *Lesbian, Gay, Bisexual, Transgender, Queer (LGBTQ) People with Cancer Fact Sheet* (2020).<sup>10</sup> Indeed, the LGBTQ community has a disproportionate burden of some chronic illnesses, like cancer, HIV, and heart disease. Gwendolyn P. Quinn et al., *Cancer and Lesbian, Gay, Bisexual, Transgender/Transsexual, and Queer/Questioning (LGBTQ) Populations*, 65:5 CA: A CANCER J. FOR CLINICIANS 384, 384-86 (2015); Ctrs. for Disease Control & Prevention, *Diagnoses of HIV Infection in the United States and Dependent Areas, 2018 (Updated)* 14 (2020) (reporting that approximately 70% of new HIV diagnoses in 2018 were among gay and bisexual men); Yi Guo et al.,

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<sup>7</sup> <https://www.nimh.nih.gov/health/statistics/mental-illness.shtml>.

<sup>8</sup> <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

<sup>9</sup> [https://ncats.nih.gov/files/NCATS\\_RareDiseasesFactSheet.pdf](https://ncats.nih.gov/files/NCATS_RareDiseasesFactSheet.pdf).

<sup>10</sup> <https://prod.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/lgbtq-people-with-cancer-fact-sheet.pdf>.



*Statin use for Atherosclerotic Cardiovascular Disease Prevention Among Sexual Minority Adults*, J. OF AM. HEART ASSOC. (Dec. 2, 2020) (collecting research on disparity in cardiovascular disease events for sexual and gender minority people).<sup>11, 12, 13</sup>

Despite the universal need for health care and the increased needs of those with chronic diseases, LGBTQ people face distinct challenges in obtaining care because of discrimination and the fear of discrimination. In one survey, 8% of LGBQ respondents who had visited a health care provider in the past year said that a doctor or health care provider had refused to see them because of their actual or perceived sexual orientation. Shabab A. Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People from Accessing Health Care*, Ctr. for Am. Progress (Jan. 18, 2018).<sup>14</sup> Nine percent said that a doctor or health care provider used harsh or abusive language while treating them. *Id.* Other studies report similar results, including that 12% of LGB people report that health care professionals blame them for their health status. Lambda Legal, *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People with HIV* 11

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<sup>11</sup> <https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.3322/caac.21288>.

<sup>12</sup> <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-updated-vol-31.pdf>.

<sup>13</sup> <https://www.ahajournals.org/doi/full/10.1161/JAHA.120.018233?af=R>.

<sup>14</sup> <https://www.americanprogress.org/issues/lgbtq-rights/news/2018/01/18/445130/discrimination-prevents-lgbtq-people-accessing-health-care/>.

(2010).<sup>15</sup> And the reported discrimination was even higher among transgender people—29% reported that a doctor or health care provider had refused to see them because of their actual or perceived gender identity; 23% had been intentionally misgendered; and 21% said a doctor or provider had used harsh or abusive language. Mirza & Rooney, *supra*.

There is good reason to expect that LGBTQ people with chronic diseases are even more likely to experience discrimination than these numbers reported for LGBTQ people generally. Those with a chronic disease often must interact with more health care providers on a more frequent basis. A 2016 study found that 55.5% of all doctor visits in the United States were related to one or more chronic conditions. Rui P. Okeyode, Ctrs. for Disease Control & Prevention, *National Ambulatory Medical Care Survey: 2016 National Summary Tables* Table 18 (2016).<sup>16</sup> For example, even long after diagnosis and initial treatment, individuals with a previous cancer diagnosis are more likely to have hospitalizations, ER visits, ambulatory surgeries, and provider visits than those without. They thus spend on average more than twice as long receiving health care in a year compared to individuals without a previous cancer diagnosis. K. Robin Yabroff et al.,

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<sup>15</sup> [https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report\\_when-health-care-isnt-caring.pdf](https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf).

<sup>16</sup> [https://www.cdc.gov/nchs/data/ahcd/names\\_summary/2016\\_names\\_web\\_tables.pdf](https://www.cdc.gov/nchs/data/ahcd/names_summary/2016_names_web_tables.pdf).

*Annual Patient Time Costs Associated with Medical Care Among Cancer Survivors in the United States*, 52:7 MED CAR. 594, 597-99 (2014). Similarly, individuals living with HIV must receive lifelong treatment from medical providers to suppress the virus, treatment that helps maintain a healthy immune system and prevent spread. Dep't of Health & Human Servs., *Evidence of HIV treatment and viral suppression in preventing the sexual transmission of HIV* (2018).<sup>17</sup> For an LGBTQ person with one of these chronic conditions, every health care visit comes with a risk of suffering discrimination from doctors or health care providers. Mirza & Rooney, *supra*.

**B. Discrimination In Health Care Harms LGBTQ People In Many Different Ways**

The harms from discrimination go beyond being denied health care. The higher levels of stress related to discrimination and marginalization has led to health behavioral issues and poor health outcomes. Guo, *supra*, at 1-2. Indeed, those higher levels of stress can directly contribute to increased risk of chronic disease like heart disease. *Id.* They also contribute to higher rates of tobacco, alcohol, and drug use, as obesity, all of which increase the risks for various chronic conditions. *Id.*

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<sup>17</sup> <https://www.cdc.gov/hiv/pdf/risk/art/cdc-hiv-art-viral-suppression.pdf>.

When LGBTQ people experience bias, humiliation, or harsh treatment at the hands of health care providers, they also can become alienated from the health care system and reluctant to seek care at all. Lambda Legal, *supra*, at 12. In one survey, roughly 29% of LGB respondents and 73% of transgender respondents felt that medical personnel would likely treat them differently because of their sexual orientation or gender identity. *Id.* Because of fears of discrimination from medical personnel, 8% of LGBTQ people in another survey avoided or postponed medical care. Mirza & Rooney, *supra*. That increased to 14% for those who had experienced discrimination due to their sexual orientation or gender identity in the past year. *Id.* The delayed or avoided medical care often includes critical preventive services—for LGBTQ people who had experienced discrimination in the past year, 17% reported delaying or avoiding seeking preventative screenings. *Id.*; see Chioun Lee et al., *The Association between Perceived Provider Discrimination, Health Care Utilization, and Health Status in Racial and Ethnic Minorities*, 19 *Ethnicity & Disease* 330 (2009) (reporting that “[p]erceived provider discrimination contributes to health disparities” and “delay” in seeking care for other minority groups).

Timely medical care and preventative screenings are vital for everyone, including LGBTQ people with diagnosed or undiagnosed chronic diseases:

- The five-year survival rates for those diagnosed at later stages of cancer are significantly lower than the rates for those diagnosed when

their cancer is less advanced. Am. Cancer Soc’y, *Cancer Facts, supra*, at 21.<sup>18</sup>

- Early treatment for multiple sclerosis is similarly critical. Multiple Sclerosis Coalition, *The Use of Disease Modifying Therapies in MS: Principles and Current Evidence* (2014; updated 2019).<sup>19</sup> A growing body of evidence indicates that early and ongoing treatment with an FDA-approved disease-modifying therapy is the best way to manage the MS disease course, prevent accumulation of disability, and protect the brain from damage due to MS. *Id.* at 14-17. MS patients face a reduction in survival of between 8 to 12 years if they do not receive proper treatment. *Id.* at 5; see Daniel M. Hartung et al., *Trends In Coverage for Disease Modifying Therapies in Multiple Sclerosis in Medicare Part D*, 38 HEALTH AFFAIRS 303 (2019).
- Timely treatment for epilepsy is also critical to reduce the risk of accident, injury, or sudden unexpected death. C.E Belgley & T.L. Durgin, *The direct costs of epilepsy in the United States: A systemic review of estimates*, 56 EPILEPSIA 1376-87 (2015).
- Early detection and treatment of HIV is not only essential for people living with HIV, but it is also necessary to help stop HIV’s spread—80% of new HIV infections are the result of someone unaware of their status or not receiving treatment. Zihao Li et al., *Vital Signs: HIV Transmission Along the Continuum of Care — United States, 2016*, 68 Morbidity & Mortality Weekly Report 267 (2019).<sup>20</sup>
- Untreated psychosis in individuals with mental illness “increases a person’s risk for suicide, involuntary emergency care, and poor clinical outcomes.” Vikki Wachino et al., *Coverage of Early*

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<sup>18</sup> <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2020/cancer-facts-and-figures-2020.pdf>.

<sup>19</sup> [https://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT\\_Consensus\\_MS\\_Coalition\\_color](https://www.nationalmssociety.org/getmedia/5ca284d3-fc7c-4ba5-b005-ab537d495c3c/DMT_Consensus_MS_Coalition_color).

<sup>20</sup> <http://dx.doi.org/10.15585/mmwr.mm6811e1>.

*Intervention Services for First Episode Psychosis*, 2 (Oct. 16, 2015).<sup>21</sup> In contrast, early intervention strategies have changed the trajectory of individuals' lives, enabling people with serious mental illnesses to live in community settings and participate fully in family and community life. *Id.*

**C. Preventing Discrimination Is Necessary To Improve Health Outcomes, Provide Better Preventative Care, And Increase Patient Satisfaction With Care**

Discrimination by health care providers also harms LGBTQ people because it pressures them to stay closeted when seeking medical care, leading to worse health outcomes for those with chronic diseases. Many studies report that discrimination can deter LGBTQ people from disclosing their sexual orientation or gender identity to health care providers. Institute of Medicine, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* 63 (2011); UC Davis Comprehensive Cancer Center, *LGBT Task Force Finds Disparities in Cancer Screening and Care* (2012)<sup>22</sup>; Liz Hamel et al., *HIV/AIDS In the Lives of Gay and Bisexual Men in the United States*, Kaiser Family Foundation (2014).<sup>23</sup> That lack of disclosure can lead to worse care. Gwendolyn P. Quinn et al., *The Importance of Disclosure: Lesbian, Gay,*

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<sup>21</sup> <https://www.medicaid.gov/federal-policy-guidance/downloads/cib-10-16-2015.pdf>.

<sup>22</sup> <https://health.ucdavis.edu/synthesis/issues/fall2012/lgbt-task-force-tackles-disparities-in-cancer-screening-and-care.html>.

<sup>23</sup> <https://www.kff.org/hiv/aids/report/hiv-aids-in-the-lives-of-gay-and-bisexual-men-in-the-united-states/>.

*Bisexual, Transgender/Transsexual, Queer/Questioning, and Intersex Individuals and the Cancer Continuum* 121 *CANCER* 1160, 1161-62 (2015).<sup>24</sup>

For example, lesbian women have multiple higher risk factors for breast cancer than heterosexual women, such as higher smoking and obesity rates, greater alcohol use, and never having completed a pregnancy; compared to straight men, gay men have a higher prevalence of human papillomavirus, which is associated with several types of cancer; and a transgender person requires screening for different conditions than an individual whose gender identity conforms to the sex they were assigned at birth. *Id.* Frequent HIV screening for gay men or transgender persons similarly helps catch and treat HIV early and helps prevent further spread of the disease. *HIV Surveillance, supra* at 7-8. Yet instead of increased screening by health care providers for these various risks, one survey found that LGBTQ respondents were less likely to receive proper screening—only 32% of female respondents had received recommended mammograms and nearly half of respondents said their providers did not talk to them about their risks of cancer or how to reduce them. UC Davis, *supra*. And more than half of gay and bisexual men reported that a doctor has never recommended they get tested for HIV, even though they account for the overwhelming majority (70%) of new

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<sup>24</sup> <https://acsjournals.onlinelibrary.wiley.com/doi/epdf/10.1002/cncr.29203>.

cases. Liz Hamel et al., *supra* at 16;<sup>25</sup> Ctrs. for Disease Control & Prevention, *Diagnoses of HIV Infection, supra*. LGBTQ people also experience higher rates of mental health disorders, rates that are at least partly attributable to the excess stress they experience because of discrimination. Wendy B. Bostwick et al., *Discrimination and Mental Health Among Lesbian, Gay and Bisexual Adults in the United States*, 84 AM. J. ORTHOPSYCHIATRY 35-45 (2014).<sup>26</sup>

Such discrimination contributes to LGBTQ people's documented lower patient satisfaction. Patient satisfaction is an important metric for health care providers that depends on many factors, including effective and clear communication between health care providers and patients, a safe environment of mutual respect that lets patients disclose information, and support by providers that empowers patients to participate in their own treatment, such as by choosing among different options. Jennifer Jabson & Charlie S. Kamen, *Sexual Minority Cancer Survivors' Satisfaction with Care* 34:1-2 J. PSYCHOSOC. ONCOL. 28, 28-30 (2016). Patient satisfaction positively correlates with better health outcomes—patients who report better satisfaction with their overall experience are more likely to complete prescribed treatment and follow care provider recommendations. *Id.*;

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<sup>25</sup> <https://www.kff.org/hiv/aids/report/hiv-aids-in-the-lives-of-gay-and-bisexual-men-in-the-united-states/>.

<sup>26</sup> <https://doi.apa.org/doiLanding?doi=10.1037%2Fh0098851>.



Ashish K. Jha et al., *Patients' Perception of Hospital Care in the United States*, 359 NEW ENG. J. MED. 1921, 1925-26 (2008).<sup>27</sup>

But unsurprisingly, discrimination against LGBTQ patients lowers their satisfaction level. Jabson, *supra*, at 28-30; Joseph B. Clift & J. Kirby, *Health Care Access and Perceptions of Provider Care Among Individuals in Same-Sex Couples: Findings From the Medical Expenditure Panel Survey (MEPS)*, 59 J. HOMOSEXUALITY 839, 839-40 (2012). For example, one study found that gay and bisexual men were almost twice as likely as heterosexual men (12% versus 7%) to report lower satisfaction with medical care, including reporting that doctors did not show them respect and did not spend enough time with them. Clift & Kirby, *supra*, at 840-42. Another study showed similar results, finding across all measured satisfaction items that LGB cancer survivors reported lower satisfaction with care than heterosexual cancer survivors. Jabson & Kamen *supra*, at 35-38.

Prohibiting medical providers from discriminating on the basis of sexual orientation or gender identity must be part of the solution to these many harms suffered by LGBTQ people with chronic conditions. Telling LGBTQ patients to avoid the harm by finding another provider is not an adequate answer. Many chronic conditions require specialized care, and in some regions there may be only one or two providers with the necessary expertise. Thus, one survey found that

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<sup>27</sup> <https://www.nejm.org/doi/pdf/10.1056/NEJMsa0804116>.

“18 percent of LGBTQ people said it would be ‘very difficult’ or ‘not possible’ to find the same type of service at a different hospital,” and 17% said the same about finding service at a different community health center or clinic. Mirza & Rooney, *supra*. Even if an alternative provider exists, finding one can delay critical treatment for chronic conditions or deter LGBTQ people from receiving or completing the treatment they need. *Supra* at pp. 11-14.

Given the discrimination that many LGBTQ people face in health-care settings, it is critical that the protections Congress adopted in Section 1557 stay in place.

## **II. NONDISCRIMINATION IN HEALTH CARE AND INSURANCE IS ESSENTIAL FOR PATIENTS WITH LIMITED ENGLISH PROFICIENCY WHO HAVE CHRONIC DISEASES**

For similar reasons, the 2020 Rule’s unlawful removal of critical protections for individuals with limited English proficiency (LEP) would wreak serious harm, especially on those individuals suffering from chronic diseases. This harm is yet another reason to enjoin the 2020 Rule.

### **A. Patients With Limited English Proficiency Face Many Barriers To Receiving Quality Health Care, Especially When They Have A Chronic Disease**

As the Department of Health and Human Services itself has recognized, “individuals with limited English proficiency experience barriers to receiving regular and adequate health care.” Dep’t of Health & Human Servs.,

Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. 31376, 31459 (May 18, 2016) (previously codified at 45 C.F.R. pt. 92). More than 25 million U.S. residents qualify as limited English proficient persons, meaning they speak, read, or write English less than “very well.” U.S. Census Bureau, *Language Spoken at Home*, American Community Survey 2018 1-Year Estimates Subject Tables, tbl. S1601 (2018).<sup>28</sup> When those individuals need health care, they must contend with the challenges of both communicating their own condition and understanding the treatments prescribed by health care providers. Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. at 31459.

Studies confirm the severity of these challenges. For instance, one study found that people with limited English proficiency have “greater gaps in their understanding of their coverage,” which can lead to under-utilization of services like preventative care. Samantha Artiga et al., *The Role of Language in Health Care Access and Utilization for Insured Hispanic Adults*, Kaiser Family Foundation (2015).<sup>29</sup> In another study comparing English-speaking and limited-English-proficient patients, limited-English-proficient patients had “[l]onger hospital stays when professional interpreters were not used at admissions and/or discharge”; “[g]reater risk of surgical delays due to difficulty understanding

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<sup>28</sup> <https://data.census.gov/cedsci/table?q=S1601&tid=ACSST1Y2018.S1601>.

<sup>29</sup> <https://www.kff.org/report-section/the-role-of-language-in-health-care-access-and-utilization-for-insured-hispanic-adults-issue-brief/>.

instructions, including how to prepare for a procedure”; and “[g]reater chance of readmissions for certain chronic conditions due to difficulty understanding how to manage their conditions and take their medications.” The Joint Comm’n, *Overcoming the Challenges of Providing Care to LEP Patients*, Quick Safety, May 2015 at 1.<sup>30</sup>

**B. Language Barriers Threaten Substantial Harm To Limited-English-Proficient Patients With Chronic Diseases**

These barriers to adequate care can become a matter of life and death for limited-English-proficient individuals with chronic conditions. As explained, those with a chronic disease often must interact with more health care providers on a more frequent basis than those without. *Supra* at pp. 10-11. For someone with limited English proficiency, every one of those interactions comes with the risks of miscommunications and misunderstandings because of language barriers. It should thus come as no surprise that people with limited English proficiency have disproportionately lower rates of cancer screening than English-proficient patients. Jennifer L. Ridgeway et al., *Closing the Gap: Participatory Formative Evaluation to Reduce Cancer Screening Disparities among Patients with Limited English*

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<sup>30</sup> <https://www.jointcommission.org/resources/news-and-multimedia/newsletters/newsletters/quick-safety/quick-safety--issue-13-overcoming-the-challenges-of-providing-care-to-lep-patients/overcoming-the-challenges-of-providing-care-to-lep-patients/>.

*Proficiency*, J. CANCER EDUC. (Feb. 12, 2020).<sup>31</sup> Although colorectal cancer is largely preventable and highly treatable with early detection, it is the second-leading cause of cancer for Asian American/Pacific Islander men. Tetine Sentell et al., *Colorectal Cancer Screening: Low Health Literacy and Limited English Proficiency Among Asians and Whites in California*, 18 (Suppl.) J. HEALTH COMMUN. 242 (2013).<sup>32</sup> Yet individuals with limited English proficiency in that group are far less likely to receive essential screening. *Id.*

The same goes for breast cancer patients with limited English proficiency—one study found that “language was the greatest barrier to understanding information and making treatment-related decisions.” Sunmin Lee et al., *What is Lacking in Patient-Physician Communication: Perspectives from Asian American Breast Cancer Patients and Oncologists*, 1 J. BEHAV. HEALTH 102, 102 (2012).<sup>33</sup> Another found that women with limited English proficiency reported fewer screening mammograms and fewer benign lumps removed. Jose L. Cataneo et al., *Disparities in Screening for Breast Cancer Based on Limited Language Proficiency*, 231 (Suppl.) J. AM. COLL. SURG. S36, S36-37 (2020). And language barriers interfere with more than just the specialized care needed for many chronic conditions. They also often disrupt basic medical care, “decreas[ing] access to

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<sup>31</sup> <https://pubmed.ncbi.nlm.nih.gov/32052262/>.

<sup>32</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3815112/>.

<sup>33</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3566873/>.

primary and preventive care” for those who speak English less than very well. Elisabeth Wilson et al., *Effects of Limited English Proficiency and Physician Language on Health Care Comprehension*, 20 J. GEN. INTERNAL MED. 800 (2005).<sup>34</sup>

Communication challenges also threaten to harm limited-English-proficient individuals with a mental illness. Limited-English-proficient persons’ mental health concerns “are more likely to go unnoticed by primary care providers,” and even when they are noticed, the ensuing care is often “poorer quality.” Maria E. Garcia et al., *Collaborative Care for Depression among Patients with Limited English Proficiency: A Systematic Review*, 33 J. GEN. INTERNAL MED. 347, 347 (2017).<sup>35</sup> Those results are particularly troubling because identity-based victimization, such as discrimination because of an individual’s limited English proficiency or culture, can lead to “a higher risk” of “poor mental health.” Maggi Price et al., *The intersectionality of identity-based victimization in Adolescence: A person-centered examination of mental health and academic achievement in a U.S.*

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<sup>34</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490205/>.

<sup>35</sup> [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5834967/pdf/11606\\_2017\\_Article\\_4242.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5834967/pdf/11606_2017_Article_4242.pdf).

*high school*, 76 J. ADOLESCENCE 185, 185 (2019) (describing effect of discrimination on children).<sup>36</sup>

Nor does the harm stop with limited-English-proficient individuals themselves: two large studies of children with asthma and one of children with diabetes found that limited-English-proficient “parents reported worse health status and quality of life for their children than [English-proficient] parents.” Monica Eneriz-Wiemer et al., *Parental Limited English Proficiency and Health Outcomes for Children With Special Health Care Needs: A Systematic Review*, *Academic Pediatrics*, March-April 2014 at 128, 131. Limited-English-proficient parents were also “more likely than English-proficient parents to report poorer knowledge and self-efficacy in managing their child’s chronic condition,” while at the same time being less likely “to report being taught how to manage their child’s chronic condition by health care providers.” *Id.*

### **C. The 2020 Rule Would Exacerbate The Harms To Limited-English-Proficient Patients With Chronic Diseases**

Despite these recognized risks, the 2020 Rule would eliminate requirements to notify patients with limited English proficiency of their rights and the availability of language assistance. The Department itself recognized that patients who know about and use reliable language assistance services “experience

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<sup>36</sup> <https://www.sciencedirect.com/science/article/abs/pii/S0140197119301538?via%3Dihub>.

treatment-related benefits,” including “enhanced understanding of physician instruction, shared decision-making, provision of informed consent, adherence with medication regimes, preventive testing, appointment attendance, and follow-up compliance.” Nondiscrimination in Health Programs and Activities, 81 Fed. Reg. at 31459; Brian D. Smedley et al., Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* 142, 191 (2003). Numerous commenters on the proposals that led to the 2020 Rule identified similar benefits from proper notice about language services and patient rights. Am. Heart Assoc., Comment Letter on Proposed Rule on Nondiscrimination in Health Programs and Activities 9-10 (Aug. 13, 2019)<sup>37</sup>; Am. Acad. of Pediatrics, Comment Letter on Proposed Rule on Nondiscrimination in Health Programs and Activities 6 (Aug. 13, 2019)<sup>38</sup>; WomenHeart: The National Coalition for Women with Heart Disease et al., Comment Letter on Proposed Rule on Nondiscrimination in Health Programs and Activities 13-15 (Aug. 13, 2019).<sup>39</sup>

The 2020 Rule’s elimination of protections for limited-English-proficient individuals would also exacerbate other types of discrimination. LGBTQ people who also have limited English proficiency will be harmed twice over—at the same

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<sup>37</sup> <https://www.regulations.gov/document?D=HHS-OCR-2019-0007-138871>.

<sup>38</sup> <https://www.regulations.gov/document?D=HHS-OCR-2019-0007-139520>.

<sup>39</sup> <https://rarediseases.org/wp-content/uploads/2019/08/NORD-2019-HCRL-1557-Patient-Coalition-Comments-FINAL-8.13.2019.pdf>.



time that they lose protections against discrimination for being LGBTQ, they will also lose access to information about their rights, how to protect themselves, and who they can turn to for help. For all these reasons, it is critical that the Court preserve the protections Congress enacted.

### CONCLUSION

For these reasons, Amici ask that the Court grant the plaintiffs' motion.

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Respectfully submitted,

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