



Mach 1, 2019

The Honorable Lamar Alexander  
 Chairman  
 U.S. Senate Committee on Health, Education, Labor and Pensions  
 428 Dirksen Senate Office Building  
 Washington, DC 20510

**Re: Lowering Health Care Costs RFI**

Dear Senator Alexander:

The 23 undersigned organizations represent millions of patients and consumers who live with serious, acute, and chronic conditions across the country. Together, our organizations work to ensure that both patient voices and interests are reflected in any debate or legislation related to the accessibility, adequacy, and affordability of healthcare for Americans and their families. The diversity and experiences of our patients enable us to draw upon a wealth of knowledge and expertise that we believe can be an invaluable resource in this discussion. We appreciate this opportunity to provide constructive feedback regarding health care costs, and we do so on behalf of millions of patients across the country who live with chronic disease, disabilities, and other health conditions.

In 2017, our organizations agreed upon three overarching principles<sup>1</sup> to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need, including the services in the essential health benefit package; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care. Enrollment should be easy to understand, and benefits should be clearly defined.

Using these principles as our benchmark, we have provided feedback and recommendations for your consideration as you begin to draft legislation that would help address the rising cost of care across our healthcare system. We appreciate your interest in the patient perspective and lowering healthcare costs, and have provided specific recommendations below.

### **Systemic Costs & Chronic Disease**

There is a wealth of information that demonstrates both the direct and indirect costs of chronic disease in the U.S. The Centers for Disease Control and Prevention (CDC) estimates that 90% of the nation's annual \$3.3 trillion in health expenditures is spent on care for people with chronic and mental health conditions.<sup>2</sup> Medicare data also shows a direct correlation with spending per enrollee increasing with the number of chronic diseases they have. Beneficiaries who have one or more chronic diseases account for more than half of Medicare all spending.

Many chronic diseases, however, are preventable or controllable with appropriate prevention, screening and disease management. Strategic investments in prevention programs not only keep people healthier, but also provide significant savings to our healthcare system over the long term. A recent study indicated that slowdowns in the rate of Medicare spending per beneficiary were due to effective use of medications that reduce cardiovascular risk factors.<sup>3</sup> Prevention programs also play a critical role in reducing tobacco-related death and disease. For example, the CDC's Tips from Former Smokers campaign has motivated over 9 million smokers to make a quit attempt, helped over 500,000 smokers to successfully quit, and saved at least 50,000 people from premature death since its inception in 2012.<sup>4</sup> Additionally, tools like the Medicare Chronic Disease Dashboard provide helpful data on chronic disease prevalence and geographic distribution, giving the government great leverage to target specific populations for prevention and reducing the impact of chronic disease. Combined with evidence-based interventions, tremendous progress can be made in reducing the impact of chronic disease with federal investments in these programs.

For some chronic diseases like arthritis, the indirect costs from lost productivity are higher than the direct medical costs. A study published in Health Affairs in 2017 showed that one in four employees from a cohort of 408,000 workers took a leave of absence due to illness and injury between 2008-2012,

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<sup>1</sup> Healthcare reform principles. American Heart Association website. [http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm\\_495416.pdf](http://www.heart.org/idc/groups/heart-public/@wcm/@adv/documents/downloadable/ucm_495416.pdf).

<sup>2</sup> National Center for Chronic Disease Prevention and Health Promotion. Health and Economic Costs of Chronic Disease. <https://www.cdc.gov/chronicdisease/about/costs/index.htm>

<sup>3</sup> Cutler DM, Gohsh K, Messer K, et al. Explaining the Slowdown in Medical Spending Growth Among the Elderly, 1999-2012. Health Affairs 38:2; February 2019. Pages 222-229 <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05372>

<sup>4</sup> Murphy-Hoefer R, Davis KC, Beistle D, King BA, Duke J, Rodes R, et al. Impact of the Tips From Former Smokers Campaign on Population-Level Smoking Cessation, 2012–2015. Prev Chronic Dis 2018;15:180051. DOI: <http://dx.doi.org/10.5888/pcd15.180051>

resulting in \$1.8 billion in lost productivity from disability leave.<sup>5</sup> People with chronic diseases were more likely to take disability leave, particularly for arthritis, depression, and cancer. Investing in prevention and encouraging plan design elements such as first-dollar coverage for primary care and prevention helps people take control of their health, keeps Americans healthy, and also helps to keep the economy healthy.

### **Individual Costs of Chronic & Serious Illnesses**

Chronic and serious illnesses also have a direct impact on patients and consumers. Within our health care system, access to medical care and services is frequently predicated on having access to high-quality, affordable health coverage. Despite historic gains since the passage of the Affordable Care Act (ACA), there are still approximately 28 million Americans who are currently uninsured or underinsured.

The connection between health insurance and health outcomes are clear and well documented. For example, Americans with cardiovascular risk factors who are uninsured or underinsured have higher mortality rates<sup>6</sup> and poorer blood pressure control<sup>7</sup> than their insured counterparts. Uninsured stroke patients suffer from greater neurological impairments, longer hospital stays,<sup>8</sup> and higher risk of death<sup>9</sup> than similar patients with adequate coverage. Uninsured and underinsured patients are also more likely to delay seeking medical care resulting in more high-cost interventions downstream. In a recent survey of patients with neuromuscular disease, one in three respondents indicated that they had delayed seeking or receiving medical care due to cost concerns.<sup>10</sup>

Many Americans continue to struggle affording high-quality insurance coverage. Even after the enactment of the ACA, studies indicate that the financial hardships from medical bills continue to impact low-income and uninsured Americans the most.<sup>11</sup> Recent regulations promulgated by the Department of Health and Human Services (HHS or Department) continue to undermine the affordability and accessibility of high-quality coverage options. Instead of making healthcare coverage more affordable for consumers and patients, as many of the regulations purported to do, non-compliant plans such as short-term, limited-duration (short-term) and association health plans (AHPs) will likely raise premium costs for others in the individual markets, confuse consumers, and leave consumers and people with pre-existing conditions vulnerable to financial and bodily harm.

While non-compliant plans frequently offer cheaper premiums, most are not required to adhere to important standards including coverage for the ten essential health benefit (EHB) categories, guaranteed issue, prohibitions on age and gender rating, prohibitions on discrimination against people

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<sup>5</sup> Gifford, Brian. "Temporarily Disabled Workers Account for a Disproportionate Share of Health Care Payment." *Health Affairs* 36:2; February, 2017. Pages 245-249.

<sup>6</sup> McWilliams JM, Zaslavsky AM, Meara E, Ayanian JZ. Health insurance coverage and mortality among the near-elderly. *Health Affairs* 2004; 23(4): 223-233.

<sup>7</sup> Duru OK, Vargas RB, Kerman D, Pan D, Norris KC. Health Insurance status and hypertension monitoring and control in the United States. *Am J Hypertens* 2007;20:348-353.

<sup>8</sup> Shen JJ, Washington EL. Disparities in outcomes among patients with stroke associated with insurance status. *Stroke* 38(3):1010-1016.

<sup>9</sup> McWilliams JM, Meara E, Zaslavsky AM, Ayanian JZ. Health of previously uninsured adults after acquiring Medicare coverage. *JAMA*. 2007; 298:2886 –2894.

<sup>10</sup> *ONEVoice: Insights and Observations from a National Survey of Adults and Families Living with Neuromuscular Disease* (Rep.). (2018). Chicago, IL: Muscular Dystrophy Association. [www.mda.org/sites/default/files/2018/12/MDA\\_OneVoice\\_Whitepaper.pdf?\\_ga=2.23259898.1327659026.1551194627-1126947336.1531846291](http://www.mda.org/sites/default/files/2018/12/MDA_OneVoice_Whitepaper.pdf?_ga=2.23259898.1327659026.1551194627-1126947336.1531846291)

<sup>11</sup> Valero-Elizondo J, Khera R, Saxena A, et al. Financial Hardship from Medical Bills Among Nonelderly US Adults with Atherosclerotic Cardiovascular Disease. *Journal of American Cardiology* 73:6; February 2019.

with pre-existing conditions, annual out-of-pocket maximums, prohibitions on annual and lifetime coverage limits, and many other critical patient and consumer protections. These plans often require consumers to spend enormous sums during the deductible portion of their benefit design, which can quickly eclipse the premium savings consumers may have while covered by one of these plans.

The affordability and integrity of state-based marketplaces has been further undermined by newly issued federal guidance relating to the ACA's Section 1332 guardrails. This misinterpretation of the guardrails will have real consequences for patients, steering people into substandard coverage, such as short-term, limited-duration plans and association health plans, which often do not cover the full range of benefits and services that patients rely upon to manage their conditions. As a result, people who find themselves with substandard coverage would – in the event of a serious diagnosis – likely encounter massive medical bills. Further, policies that could be implemented under this new interpretation could fundamentally alter the risk pool for a state's individual marketplace, making comprehensive coverage unaffordable for the patients who rely on it. The resulting lack of access to care could have devastating short- and long-term consequences for the millions of patients we represent.

We urge you and your colleagues to act to limit the sale of non-compliant plans and mitigate the impact of the 1332 guidance. Constructive Congressional action could help stabilize the market and ensure that American consumers have access to the healthcare they need when they get sick.

### **Increasing Access can Reduce Individual & Systemic Costs**

Our organizations recognize the barriers that currently exist for many Americans to access quality and affordable healthcare. There are a number of policy solutions that can improve access to quality healthcare.

#### Medicaid Expansion

There are currently over two million people who are in the “coverage gap.”<sup>12</sup> These individuals live in states that have not opted to expand Medicaid eligibility pursuant to the ACA. They earn less than 100 percent of the federal poverty level, making them ineligible for an advanced premium tax credit (APTC), but they also do not qualify for their state's standard Medicaid program because their income exceeds the limit or they do not have any dependent children.

The evidence is clear that Medicaid expansion has important health benefits for patients. For example, one study found an association between Medicaid expansion and early stage cancer diagnosis.<sup>13</sup> Lung cancer five-year survival is only five percent for those diagnosed at a late (distant) stage after the tumor has spread, but increases to 56 percent for those diagnosed at an early (local) stage before the tumor has spread.<sup>14</sup> For patients with asthma, another study found that Medicaid expansion was associated with improvements in quality measures related to asthma management at federally qualified health centers, helping patients to breathe easier.<sup>15</sup>

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<sup>12</sup> <https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>

<sup>13</sup> Aparna Soni, Kosali Simon, John Cawley, Lindsay Sabik, “Effect of Medicaid Expansions of 2014 on Overall and Early-Stage Cancer Diagnoses”, *American Journal of Public Health* 108, no. 2 (February 1, 2018): pp. 216-218. Available at <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2017.304166>.

<sup>14</sup> [SEER Cancer Statistics Review, 1975-2015](#)

<sup>15</sup> Megan B. Cole, Omar Galárraga, Ira B. Wilson, Brad Wright, and Amal N. Trivedi. “At Federally Funded Health Centers, Medicaid Expansion Was Associated With Improved Quality Of Care,” *Health Affairs* 36, no. 1 (January 2017): pp. 40-48. Available at <https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.2016.0804>.

Our organizations encourage Congress to work with states and the Centers for Medicare and Medicaid Services (CMS) to promote Medicaid expansion and encourage states to expand their Medicaid programs to 138 percent of the federal poverty level if they have not done so already. One way to do this is to incentivize states to expand by offering an initial higher FMAP for the expansion for the first five years of expansion if the state expands their Medicaid program.

### *Improving Access to Medicaid*

As mentioned above, to access quality care, Americans need to have quality insurance coverage. A critical part of insuring Americans is the Medicaid program. Since the passage of the ACA, Medicaid enrollment has increased by 27.5 percent,<sup>16</sup> providing quality healthcare for millions of previously uninsured Americans. Unfortunately, over the past two years, CMS has encouraged and approved waiver proposals that limit access to the Medicaid program through work and community engagement requirements in addition to other policies that jeopardizing low-income Americans' access to quality care.

The high cost burden of chronic diseases including heart disease, lung disease, diabetes, cancer and oral conditions impact both the public and financial health of states. Community-based efforts aimed at addressing social determinants – such as Healthier Tennessee – can bring extraordinary benefit to states, but will only succeed if low-income and high-risk individuals also have quality and affordable healthcare. A 2015 study conducted for the (Tennessee) Governor's Foundation for Health and Wellness by the Sycamore Institute estimated the financial impact of diabetes (\$1 billion), hypertension (\$336 million) and cardiovascular disease (\$3.9 million), which affect approximately 460,000 Tennesseans.<sup>17</sup>

Improving access to primary care interventions can successfully prevent many of these conditions when they are most treatable and least costly. Currently, 16 percent of Tennesseans live in poverty, including one in four children and one in ten seniors.<sup>18</sup> Poverty only increases the need for affordable, accessible and adequate care. Enacting additional barriers to care, such as work requirements, will only exacerbate the challenges already facing Tennesseans. By reducing barriers to care and enhancing the availability and accessibility of care through complete Medicaid expansion without barriers, Tennessee and other states have the opportunity to ensure a healthier population and workforce.

However, increasing administrative and compliance requirements will likely decrease the number of individuals with Medicaid coverage, regardless of any policies to exempt patients. Arkansas is currently implementing a work requirement policy that requires Medicaid enrollees to report their hours worked or their exemption in order to maintain their coverage. In the first six months of implementation, the state has terminated coverage for 18,164 individuals and locked them out of coverage until January 2019.<sup>19</sup> In another case, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.<sup>20</sup> Battling administrative red tape in

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<sup>16</sup> <https://www.macpac.gov/subtopic/medicaid-enrollment-changes-following-the-aca/>

<sup>17</sup> Melton, Courtney and Mandy Pellegrini. The Sycamore Institute. <https://www.sycamoreinstitute.org/2017/11/15/cost-chronic-disease-tennessee/>. Accessed February 24, 2019.

<sup>18</sup> Melton, Courtney. The Sycamore Institute. <https://www.sycamoreinstitute.org/2018/12/18/income-poverty-education-insurance/>. Accessed February 24, 2019.

<sup>19</sup> Arkansas Department of Health and Human Services. Arkansas Works Program December 2018. Accessed at: [https://www.arktimes.com/media/pdf/12.18 - aw\\_work\\_requirements\\_report.pdf](https://www.arktimes.com/media/pdf/12.18 - aw_work_requirements_report.pdf).

<sup>20</sup> Tricia Brooks, "Data Reporting to Assess Enrollment and Retention in Medicaid and SCHIP," Georgetown University Health Policy Institute Center for Children and Families, January 2009.

order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious consequences for people with serious, acute, and chronic diseases. Hinging ones' health care coverage on their ability to find and maintain work penalizes those in the Medicaid population for their poverty and locks them out of coverage, which will likely further perpetuate the barriers that prevented them from holding work in the first place. These policies increase the potential harm to low-income patients and can contribute to rising costs. We therefore urge you in your role as Chairman, to communicate with the Administration and your Federal and State colleagues about the harms of these proposals on the cost of care in our country and the impact on low-income Americans.

#### *Expand Advanced Premium Tax Credits*

Congress should also work to address the of lack of affordable health plans for many Americans, including those with moderate incomes, by acting to increase the number of people eligible for APTCs. Currently the APTCs are only available for consumers making between 100 and 400 percent of the federal poverty level. By increasing the income eligibility to receive an APTC, more consumers would be able to afford health insurance on the exchange. This has the potential to improve the risk pool in the exchanges as well as to continue to stabilize these markets.

#### *Administrative Actions Resulting in Increased Out-Of-Pocket Costs*

Most recently CMS has undermined the intent of Congress by arbitrarily proposing to change the premium adjustment factor formula for calculating changes to subsidies, out-of-pocket caps, and other costs of private insurance. While CMS previously calculated the premium adjustment factor based on employer-sponsored insurance premiums, CMS would now use average private health insurance premiums in the formula - raising the premium adjustment factor by 3.6 percent from 2019. Should this proposal be finalized as drafted, CMS anticipates that premiums for approximately 7.3 million subsidy-eligible individuals and families who purchase insurance in the ACA marketplaces could increase by up to \$220<sup>21</sup> resulting in approximately 100,000 consumers losing their health insurance coverage in 2020 alone. The proposed change to the premium measure will result in a faster growth of the net premiums paid by consumers on the Marketplaces, and will trigger faster growth in the maximum out-of-pocket (MOOP) limit paid by all Americans, including those with large group employer coverage.

Changes in the premium adjustment formula are unnecessary and fail to protect consumers from arbitrary increases in cost for all consumers - both on and off the exchange. Congress should work with the Administration to improve affordability. Below we discuss policy that we believe would improve affordability and quality of coverage. However, we also encourage congressional leaders to urge the Administration not finalize the proposed formula change in the final 2020 Notice of Benefit and Payment Parameters.

#### *Reinsurance*

From 2014 to 2016, the federal government operated the Transitional Reinsurance Program (TRP), which established a national reinsurance program to stabilize the insurance market. Reinsurance reduces the risk to insurers of covering high-cost patients thus creating stability in the markets. This

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<sup>21</sup> Aviva Aron-Dine and Matt Broaddus. "Change to Insurance Payment Formulas Would Raise Costs for Millions With Marketplace or Employer Plans." Center on Budget and Policy Priorities. Jan. 18, 2019, available at <https://www.cbpp.org/sites/default/files/atoms/files/1-18-19health.pdf>.

protects Americans from significant premium increases by offsetting the costs of sicker and more costly enrollees. While the TRP faced several implementation challenges, the program was critical in mitigating the risk associated with very high-cost enrollees and stabilizing premiums during its existence. The Alexander-Murray market stabilization package considered in the last Congress envisioned an extended federal reinsurance program, and we urge Congress to create such a program to lower costs for consumers in the individual market, while saving taxpayer dollars.

While there has been no nationwide, federal reinsurance program since 2016, reinsurance programs in the states have shown promising results in controlling premium growth and, in some cases, significantly reducing premiums. Eight states currently operate reinsurance programs, leveraging federal flexibility to keep premium costs down for consumers. Given the proven benefits of reinsurance as a premium-limiting approach,<sup>22</sup> Congress should consider statutory changes to simplify the process for states to establish reinsurance programs through existing or novel authorities.

### Transparency

We urge the Committee to consider ways it can improve consumers' access to meaningful and actionable information about health care costs. We are encouraged that CMS and Congress are considering a variety of legislative and regulatory approaches to empower consumers to make more informed decisions about their health care. We support efforts that would require insurers to disclose health cost information to consumers in a user-friendly format that can be easily understood.

Any attempt to legislatively address transparency within our healthcare system should be grounded in the consumer experience. This information could include a consumer's anticipated costs for services within a certain timeframe, and the anticipated cost for common services and coverage scenarios. In particular, ensuring insurers provide consumers access to an out-of-pocket cost calculator for covered services for both in and out-of-network providers would assist consumers in making decisions and help them shop for the most affordable services from the providers that are right for them. However, attempts to address transparency must also take into consideration patients' or consumers' ability to act on this information. Limited provider networks, medical facilities, or specialists, amongst other factors, may limit the ability for patients to shop around or take other steps that would help reduce costs.

Claims data transparency should also be increased, so that health policy analysts can compare the number of denials for services in Marketplace plans compared to employer-based plans. This analysis will be critical as we seek to ensure that insurers are covering all essential health benefits and are not denying coverage for these critical benefits in a systematic way under their plans. We look forward to working with legislators to both improve the patient experience and decision-making process in addition to improving understanding about how issuers and providers are handling claims.

### **Conclusion**

Our organizations represent millions of patients, individuals, caregivers, and families who need access to quality and affordable healthcare regardless of their income or geographic location. We appreciate the opportunity to provide our recommendations in response to the RFI. We look forward to working with

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<sup>22</sup> For example, Maryland insurers in 2018 initially proposed an average increase in premiums for 2019 plans of 30%. Following the approval of a reinsurance waiver in Maryland, insurers subsequently revised their rate filings to *decrease* by 13.7%, on average, from the previous year. Louise Norris. "Maryland Health Insurance Marketplace: History and News of the State's Exchange." HealthInsurance.org. Dec. 16, 2018. <https://www.healthinsurance.org/maryland-state-health-insurance-exchange/>.

you and your Congressional colleagues on reducing costs across our healthcare system during the 116<sup>th</sup> Congress.

If you have any questions or would like to discuss these comments further, please contact Katie Berge, American Heart Association Government Relations Manager, at [katie.berge@heart.org](mailto:katie.berge@heart.org) or 202-785-7909.

Sincerely,

Adult Congenital Heart Association  
ALS Association  
American Heart Association  
American Kidney Fund  
American Lung Association  
Arthritis Foundation  
Chron's & Colitis Foundation  
Chronic Disease Coalition  
Cystic Fibrosis Foundation  
Epilepsy Foundation  
Family Voices  
Global Healthy Living Foundation  
Hemophilia Federation of America  
Lutheran Services in America  
March of Dimes  
Muscular Dystrophy Association  
National Alliance on Mental Illness  
National Health Council  
National Hemophilia Foundation  
National Multiple Sclerosis Society  
National Patient Advocate Foundation  
Susan G. Komen  
WomenHeart: The National Coalition for Women with Heart Disease