

# IN THEIR OWN WORDS

## PART 2

### **ARIZONANS AND THEIR STRUGGLE WITH HIGH HEALTH CARE COSTS**

# Introduction

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Since its passage in 2010, the Patient Protection and Affordable Care Act (ACA) has fundamentally altered the landscape of American health care, making care more affordable and easier to access. The ACA introduced a range of provisions that have improved people's health care, including requirements that insurers help cover prescription drugs.<sup>1</sup> The law stopped short, however, of preventing surprise medical bills and instituting systemic changes in how drugs are priced and paid for. This lack of broad action did not start with the ACA and is a long-standing, uniquely American issue. The United States, on average, spends twice as much on health care as other large, wealthy countries – in 2020, health spending per person in the United States was \$11,945, compared with \$5,736 in the average comparable nation.<sup>2</sup> On prescription drugs, the United States spends two times the amount as its counterparts.<sup>3</sup> Unexpected, expensive medical bills also threaten Americans' access to affordable care and too often force patients to take on medical debt, which impacts more than 100 million people in the United States.<sup>4</sup>

This distinctly American problem stems in large part from the many stakeholders involved in propping up the health care system: hospitals, insurance companies, pharmaceutical companies, and pharmacy benefit managers. These parties have significant financial stakes in drug costs and surprise bills, and they spend millions of dollars lobbying Congress to protect their financial interests.<sup>5</sup> Despite these challenges, there has been promising progress to address rising health care costs. The No Surprises Act, which took effect in January 2022, bans common types of unexpected medical bills, saving Americans from the fear of receiving surprise bills for out-of-network or emergency care. Congress has yet to take action, however, to lower the price of prescription drugs. While lawmakers have considered lifting the ban on Medicare's ability to negotiate drug prices, proposals to permit negotiation, including in the Build Back Better Act, have stalled in the United States Senate. Lawmakers are considering Medicare negotiation again in a

budget reconciliation package known as the Inflation Reduction Act of 2022.<sup>6</sup>

This report examines the impact that high prescription drug prices and surprise medical bills have on people's lives. Honest Arizona spoke to experts and conducted focus groups with Arizonans about their experiences paying for medications and medical services and the steps they take to afford critical, but often expensive, care.<sup>7</sup> Based on these conversations, this report underscores that more action is needed to make health care more affordable and predictable.

**Focus groups were conducted online on June 23, 2022 with participants in Arizona who are insured under the Affordable Care Act or have someone in their household on ACA insurance: one group of women and one group of men (across racial backgrounds), and one group of Latino participants (of mixed gender). The groups ranged from 6-7 people, spanning the ages of 18 to 60+, across political parties and education levels.**

## High Health Care Costs in the United States Impact Focus Group Participants' Life Decisions

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High health care costs are a major problem in the United States. A Johns Hopkins University study showed that the United States spends more on health care, per capita, than other similar countries – due to high prices, not increased care.<sup>8</sup> In 2021, the United States spent an estimated \$12,318 per person on health care, more than comparably wealthy countries such as Germany and Canada.<sup>9</sup> Because they are forced to pay extremely high costs, Americans often have to make tradeoffs to pay for their care.<sup>10</sup> A Kaiser Family Foundation (KFF) health tracking poll found that one in six Americans have put off vacations, cut

household expenses, or reduced overall spending in order to pay medical bills.<sup>11</sup>

In the focus groups, high costs dominated how participants thought about their own health care coverage, as shown by Figure 1. Most participants struggled with costs and shared that they cut personal spending in order to pay for health care. One participant said they gave up their cable subscription, citing it as one of their largest monthly expenses other than their premiums. For other focus group participants, high health care costs have impacted key life decisions. At least two participants said that they have postponed retirement and continued to work because they are not yet eligible for Medicare and cannot afford to purchase their own coverage. And while the ACA improved portability of care, so that Americans are less likely to lose insurance when they leave a job, one participant nonetheless reported that they remained in a job they did not like because of the comprehensive insurance package it provided them. In 2021, 16 percent of workers in the United States reported having a similar experience.<sup>12</sup> One participant knew of two people who declined to get married because of high health care costs, as marriage would have made one of the individuals ineligible for Medicaid.



High drug prices require Americans to search for ways to afford their prescriptions. Twenty-three percent of Americans report not filling a prescription, cutting pills in half, or skipping doses of a medicine to manage their costs and care; 10

percent have purchased or attempted to purchase prescription medications from outside the United States; and 8 percent traded, purchased, or accepted donations of leftover medications from another person.<sup>13</sup> Some focus group participants also searched for discounts online when insurance does not cover enough of the cost.

**“I have known other people that have really struggled with health care costs. Also, I’ve known people who, they didn’t get married because their wife, but not official wife, would be getting Medicaid, but if they got married, they’d be making too much money. So, they don’t get married.... And they do that, even though they’d rather get married and have good health care.”**

Rationing medication or skipping doses is a particularly dangerous way some Americans manage high drug costs – three in 10 adults reported not taking their medicines as prescribed at some point in the past year because of the cost.<sup>14</sup> One focus group participant’s prescription costs have led them to ration their medication when they have a “good couple of months,” even though skipping doses can lead to health complications that may cause additional high health care costs.<sup>15</sup> Another participant reported trying five different drugs that were more affordable than the brand-name drug they were prescribed. These other medications, however, were “horrible” for them, and they ultimately chose to pay the expensive cash price for the brand-name drug.

**“You don’t have the money for it, you know? And when I do have a good couple of months and I’m going to get it, I ration it. You know? So yeah, I’m disgusted by the cost of prescription drugs.”**

Some Arizonans manage high drug costs in the United States by using a method distinctly available to them: crossing the border to Mexico to buy their medications for less. In every focus group, multiple

participants admitted they have, or someone they know has, crossed the border to seek prescription drugs in Mexico, noting that the over-the-counter costs in Mexico are much cheaper. Neighboring states, California and Utah, also have high rates of drug tourism to Mexico.<sup>16</sup> Some prescription medications are 40 to 60 percent cheaper in Mexico than in Utah, leading Utah's Public Employee Health Plan to begin paying for patients who need certain drugs to travel to Mexico to purchase them.<sup>17</sup> The United States International Trade Commission estimated that, in 2019, close to 1 million people in California alone would travel to Mexico for health care, including to purchase prescription drugs.<sup>18</sup> In Arizona, approximately 6,000 people pass through the Yuma Port of Entry every day to have medical procedures in Mexico.<sup>19</sup>

**“All of my prescriptions, I get over the counter in Mexico, and it’s way cheaper.”**

**“The most obvious thing is how expensive it is here, and so people are looking for more affordable options and if [going to Mexico is] the only thing we can come up with, that’s what we do.”**

Another strategy to mitigate high drug costs is using companies that subsidize prescription drugs. One participant shared that, to find the most affordable drugs, they compared prices with GoodRx – a company that provides free drug coupons for discounts on medications – but expressed confusion as to why their medications were cheaper via this method than with their own insurance. This led them to feel “lied to about the cost of prescription drugs.” As Zaida Dedolph, the Director of Health Policy at Children’s Action Alliance, explained, there seems to be “some kind of secret hierarchy . . . about who can get the cheap drugs” in the United States. One of the founders of GoodRx, Doug Hirsch, acknowledges that GoodRx “exists in large part because the U.S. supply chain is so broken.”<sup>20</sup>

**“I had to take Enbrel for my knee. And that medication, when it was all said and done, it was almost like \$50,000 - \$60,000. I was under my parents’ insurance and we paid very little, but to see the cost of it without insurance was unbelievable. And that’s the treatment that made me better. So I can’t imagine someone not having access to what I had to be better.”**

## **Focus Group Participants Find Prescription Drugs are Difficult to Afford and Some Are “Disgusted” by the Prices**

Drug prices are 2.5 times higher in the United States than in other nations.<sup>21</sup> As a result, Americans spend roughly \$1,300 each year on prescription drugs, double the per capita spending in many peer nations.<sup>22</sup> In Arizona, prescription drug prices continue to increase, outpacing income growth and making drugs more unaffordable over time. Between 2015 and 2019, the average annual cost of prescription drug treatment increased 26.3 percent while the annual income for Arizona residents only rose 15.6 percent.<sup>23</sup> Certain groups are more likely to report difficulty affording medication, including those who are spending \$100 or more per month on their prescriptions, those who take four or more prescription drugs, and those with annual incomes under \$40,000.<sup>24</sup> More than four in 10 Americans who have health insurance still struggle to pay for their medications.<sup>25</sup> These high costs lead nearly 80 percent of Arizonans to consider the cost of prescription drugs unreasonable.<sup>26</sup> In the focus groups, participants broadly agreed that the costs consumers are expected to pay for vital prescription drugs are too high – “ridiculous,” as one put it.

## Who Has Difficulty Affording Their Prescription Drugs?

Percent who say it is difficult to afford the cost of their prescription medicine:

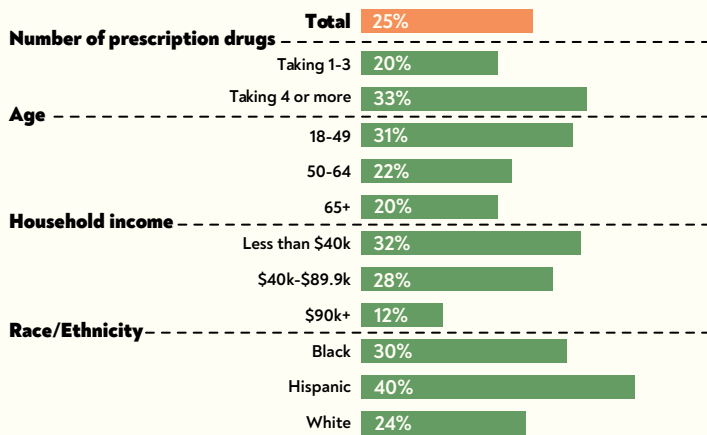


Figure 2. Graph adapted from Kaiser Family Foundation.

**“I feel disgusted by the cost of prescription drugs...It’s not a choice [that I need my medication]. It’s not from something I’ve done to myself.”**

**“I’ve gone to a doctor’s appointment, they’ve prescribed medication, but I found out that it’s not covered and I have to pay for it out of pocket... It feels like a shock to me.”**

With the cost of necessities such as food, rent, and medication increasing, paying for prescription drugs is particularly difficult. Older Americans who have fixed incomes are hit hardest by external inflation factors. Nearly 50 million of 62.2 million Medicare beneficiaries depend on Part D for prescription drug coverage.<sup>27</sup> Those enrolled in Part D prescription drug plans are sometimes exposed to a coverage gap, or the “donut hole,” when they fill prescriptions for brand-name medications. After insurance and copay spending reaches \$4,430 for covered drugs, individuals have to pay 25 percent of prescription costs out of pocket until they spend \$7,050, at which point they enter the “catastrophic coverage” level and insurance covers their drug costs again.<sup>28</sup> In 2019, 1.5 million Medicare Part D enrollees had out-of-pocket spending above the catastrophic threshold.<sup>29</sup>

For many, paying almost \$3,000 out of pocket is not affordable. One participant shared that their mom, a retiree in her mid-seventies, is struggling to pay for her heart medication after falling into the donut hole. They shared the shock of having prescription costs covered to “all of a sudden...[having] a huge gap that she has to pay.” The ACA included a provision to help non-low-income Part D enrollees shoulder large prescription drug costs.<sup>30</sup> The provision phases out the coverage gap by gradually reducing the share of total drug costs paid by enrollees, from 100 percent before 2011 to 25 percent in 2020. Yet some expensive drugs are still unaffordable, even with only 25 percent responsibility for the consumer.

A 2019 federal report found that 3.5 million Americans aged 65 and older struggled to afford their prescriptions, with individual enrollees’ spending on prescription drugs in Medicare Part D averaging about \$2,700 per year.<sup>31</sup> Seniors in the United States have the highest rate of not taking prescription drugs due to costs among 11 comparable high-income countries.<sup>32</sup> Protecting older Americans against system-wide issues, such as the donut hole, that leave them vulnerable is critical in ensuring access to essential drugs.

## Focus Group Participants are Still Afraid to Seek Health Care, Worrying About Extraordinary Bills They Cannot Afford

In addition to high prescription drug costs, Arizonans have also faced unexpected and expensive bills for medical care. The United States has relatively few regulations on what insurance must cover and what hospitals and doctors are allowed to charge, leading to distinctly high prices.<sup>33</sup> Fortunately, the No Surprises Act, which took effect in January 2022, helps prevent Americans from incurring crippling medical debt.<sup>34</sup> The law requires private health plans to cover all out-of-network provider bills for services at

in-network medical facilities and emergency room bills.<sup>35</sup> It also ensures that uninsured and self-pay patients receive key information about the price of their care. Prior to the law's passage, surprise bills, which stem from patients unexpectedly receiving high charges for out-of-network care, were common; 57 percent of American adults report having been surprised by a medical bill that they thought would be covered by insurance and nearly 20 percent of hospital visits resulted in surprise medical bills.<sup>36</sup> In Arizona, 2017 data show that 16 percent of emergency room visits and 23 percent of in-network inpatient stays led to out-of-network charges.<sup>37</sup>

**“[The No Surprises Act helped] because I had an anesthesiologist that was going to charge me \$2,400 over what their agreed-upon price was. And so Cigna actually went after them and was like, ‘No... you cannot do that.’ So, I mean, it’s helped me out.”**

Many focus group participants recalled receiving unexpected medical bills with amounts ranging into the thousands - surpassing the average bill amount of \$628 (based on 2016 data).<sup>38</sup> One focus group participant received a \$20,000 surprise bill after their daughter was injured in a biking accident and treated in an out-of-network emergency room. This incident was a significant financial burden, costing their family over \$10,000 even after insurance covered a portion of the expenses. Had this situation occurred after the No Surprises Act passed, the participant likely would have been saved from the stress and significant financial burden of having to pay for the out-of-network care their daughter received.

For many, covering the cost of a surprise medical bill is out of reach, with nearly half of American adults claiming they would not be able to cover a \$500 bill in full.<sup>39</sup> For individuals with limited assets and income, any small unexpected medical expense can be unaffordable.<sup>40</sup> The high cost of care in the United States has resulted in approximately

16 million people – six percent of all adults – owing over \$1,000 in medical debt.<sup>41</sup>

**“I tried to ask my insurance how much they would cover... They said, ‘We don’t know yet, you have to do [the test] first. And then we’ll tell you how much you’ll owe.’ And that’s a surprise medical bill.”**

While the No Surprises Act protects consumers from surprise out-of-network and emergency medical bills, focus group participants had a broader definition of surprise bills than policy-makers. As one participant put it, the unexpectedly high cost of care means that “every medical bill is a surprise.” Some surprise bills participants reported receiving were the product of insurance covering less than expected, or none, of the costs associated with important medical procedures.



**said they were very or somewhat worried about being able to afford unexpected medical bills in 2020 (before the No Surprises Act took effect).**

Figure 3. Source: KFF Health Tracking Poll (conducted February 13-18, 2020).

In 2020, about two-thirds of Americans said they were either “very worried” (35 percent) or “somewhat worried” (30 percent) about being able to afford unexpected medical expenses.<sup>42</sup> Participants spoke to the stress that medical bills cause. One focus group participant shared that they “fear going to the doctor” because of the cost. Their worries stemmed from receiving bills in the mail after their visit and being told that certain procedures or medication they had received during their surgery were going to cost more since their insurance did not cover them. To lessen the

potential of receiving an unexpected bill, some focus group participants opted to pay out-of-pocket for care. The stress of paying for medical bills is caused by a complicated health system with extraordinarily high prices.<sup>43</sup>

**“I kind of fear going to the doctor.... I was like going to the doctor and all of a sudden, just some random tests they did, I’m getting a bill in the mail. It was like, without being told, ‘Okay, this is going to cost you extra. Your insurance doesn’t cover things.’ So for me, I started paying out of pocket for a lot of things instead of using my insurance, instead of not knowing how much a bill’s going to be that arrives later on after that visit.”**

## **Popular Policy Solutions to Lower Prescription Drug Costs Currently Under Consideration**

There are popular, common-sense paths forward to lowering health care costs that have momentum in Congress. The current budget reconciliation package, known as the Inflation Reduction Act of 2022 (IRA), includes provisions that would allow Medicare to negotiate lower drug prices, cap Part D enrollees’ prescription spending at \$2,000 per year, and force pharmaceutical companies to pay rebates if they increase drug prices faster than the rate of inflation.<sup>44</sup> All of these solutions are broadly popular – a September 2021 poll found that at least 84 percent of Arizonans favored each of these proposals, and Medicare negotiation, specifically, received 94 percent support.<sup>45</sup>

The drug pricing provisions in the IRA would result in savings on prescription drugs for Medicare beneficiaries, people on private insurance plans, and the federal government. For seniors, the bill

caps out-of-pocket prescription expenses at \$2,000 per year, which will prevent some patients from falling into the donut hole. The bill’s Medicare negotiation proposal will also result in savings. The similar negotiation provisions in the Build Back Better Act, which stalled in the winter of 2021, were estimated to save \$79 billion over the next decade.<sup>46</sup> If Congress allows Medicare to negotiate the price of some prescription drugs, Part D premiums, specifically, could decline 15 percent by the end of the decade, and overall drug prices would be reduced, saving enrollees thousands of dollars.<sup>47</sup> Passing legislation to lift the ban on Medicare negotiation would also benefit consumers on private insurance plans, reducing out-of-pocket drug costs and premiums.<sup>48</sup>

Focus group participants expressed overwhelming support for these policy proposals. In one group, some participants, when informed that the Department of Veterans Affairs (VA) is allowed to negotiate lower prices for prescription drugs but Medicare is not, expressed that they felt this status quo is unfair and that they, too, should have access to lower drug prices.

**“I don’t think that’s very fair. I don’t like that. I do believe the vets should get their just due and more. I appreciate their service and they shouldn’t even have to be worried about their medical bills, actually. Why can’t we have it?”**

**“It doesn’t sound fair. I could be wrong but most people that are on Medicare are retired or dealing with some kind of thing. They can’t work anymore so if the VA, which again represents the retired community, even though they’re veterans, have the ability to control the cost, why can’t Medicare?”**

# Most Adults Favor Several Actions To Lower Drug Costs

Percent who favor each of the following actions that would keep prescription drug costs down:

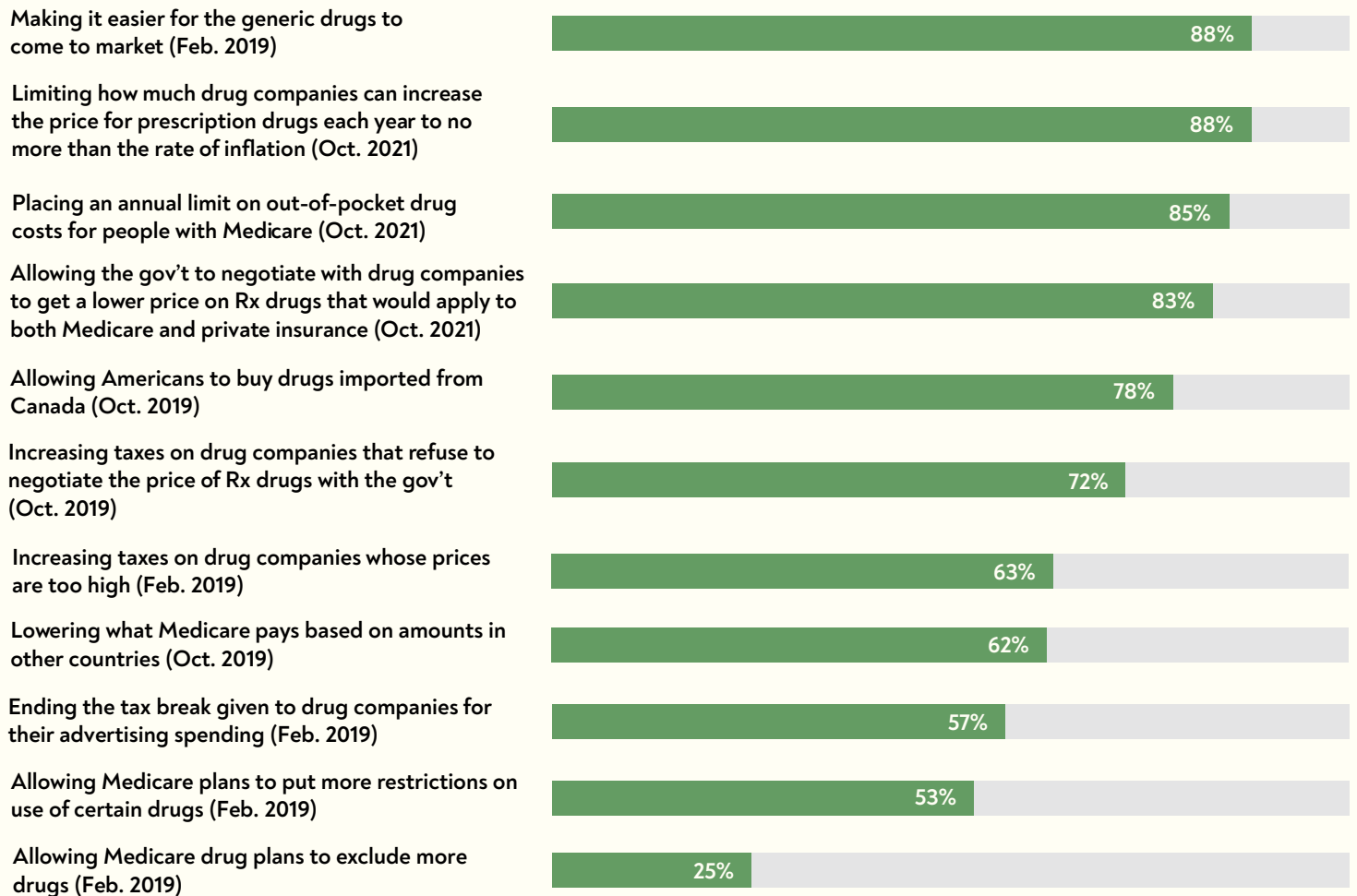


Figure 4. Graph adapted from Kaiser Family Foundation.

## Conclusion

The health care costs Arizonans face come not only from insurance premiums and copays, but also from expensive medical care and prescription drugs. The No Surprises Act has made strides in providing consumers with necessary protections against particularly common and costly surprise medical bills. Health care costs of all types, however, continue to prevent patients from seeking care and impact life decisions, spending habits, and medical treatment. Lawmakers can take action to address these issues.

The astronomical costs of prescription drugs have led Arizonans to ration their medication and purchase it outside of the country. The prescription drug pricing model, the Medicare donut hole, and

Medicare's inability to negotiate prescription drug prices continue to keep costs high for consumers. With millions of Americans suffering from chronic conditions and some spending thousands of dollars on life-sustaining medication, Congress must pass the Inflation Reduction Act to ease the financial burden on Arizonans.<sup>49</sup>

**The next report in this series will focus on the stakeholders responsible for high health care costs and outline how partisan inaction and opposition have prevented elected officials from regulating corporate actors in the health care industry.**



# Endnotes

- <sup>1</sup> Conti, R. (2020, March 1). How the ACA Reframed the prescription drug market and set the stage for current Reform Efforts. Retrieved 24 July 2022 from Health Affairs website: <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2019.01432>.
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- <sup>7</sup> Focus groups were conducted online on June 23, 2022 with participants in Arizona who are insured or have someone in their household who is insured under the Affordable Care Act: one group of women and one group of men (across racial and educational backgrounds), and one group of Latino participants. Honest Arizona interviewed 3 experts for their insights into the health landscape in Arizona: Janette Pineulas, an ACA Navigator in Tucson, Arizona, Zaida Dedolph, Health Policy Director at Children's Action Alliance, and Will Humble, the Executive Director of the Arizona Public Health Association and former Agency Director at the Arizona Department of Health Services.
- <sup>8</sup> U.S. Health Care Spending Highest Among Developed Countries. (2019, January 7). Retrieved 25 July 2022 from Johns Hopkins Bloomberg School of Public Health website: <https://publichealth.jhu.edu/2019/us-health-care-spending-highest-among-developed-countries>.
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<sup>18</sup> Ibid.

<sup>19</sup> Esquer, N., Hersch, T., & Seiden, D. (2019, May 19). Medical tourism continues to pump life into Border Region. Retrieved August 2, 2022, from Chamber Business News Website: <https://chamberbusinessnews.com/2019/02/06/medical-tourism-continues-to-pump-life-into-border-region/>

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<sup>21</sup> Mulcahy, A. W. (2021, January 28). Prescription drug prices in the United States are 2.56 times those in other countries. Retrieved 20 July 2022 from RAND Corporation website: <https://www.rand.org/news/press/2021/01/28.html#:~:text=Levels%20of%20Sleep-,Prescription%20Drug%20Prices%20in%20the%20United%20States,Times%20Those%20in%20Other%20Countries&text=Prescription%20drug%20prices%20in%20the%20United%20States%20are%20significantly%20higher,a%20new%20RAND%20Corporation%20report.>

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