Pioneering a New Approach to Uniquely and Deeply Understand People's Needs



What we've learned and how it has informed our work

USofCare launched an intensive listening initiative in 2019 to gather insights that can inform our work toward ensuring that every single person has access to quality, affordable health care regardless of health status, social need, or income. For too long our current health care system has been influenced by partisan political debates, health care industries, and special interests, rather than the needs of people. In order to shift that dynamic we need to fully understand the shared and different needs of people and use those findings to inform and prioritize the most pressing policies.

Through our research, USofCare has identified that people want to make sure several key improvements to our health care system are prioritized by our national and state leaders. These include passing policies that reduce the cost of health care, make coverage dependable, ensure the system is accessible and easy to navigate, and increase personalized care while maintaining quality across the system.

This document outlines our approach over the year, what we have learned - including the needs of people during the pandemic - and how we have applied these learnings to United States of Care's priorities and scope of work in 2020.

What We Learned

Our comprehensive approach allowed us to go beyond the traditional polling and get closer to fully understand people's health care needs and concerns. We know that the complexity and HYPER-POLITICIZED nature of our health care system contributes to ANXIETY, CONFUSION, and DISENGAGEMENT, and keeps people from getting the care they need. We learned that people share a variety of WORRIES related to the coronavirus pandemic that cut across demographics and geography. And, as gaps and DISPARATE HEALTH OUTCOMES have been illuminated by the pandemic, the public is calling for an improved health care system that emerges stronger than before.

Prior to the pandemic we had over 40 hours of conversations with people. These discussions took place at a kitchen table in San Diego, California; at a Red Hot and Blue restaurant in Dallas, Texas; on the sidewalks of Philadelphia, Pennsylvania; and with people in Missouri, Minnesota, Florida, and Washington. When the pandemic hit in March, we shifted not only the whole organization's priorities, but also our approach to how we framed our conversations with people and the questions we asked to better reflect their needs and concerns. Our <u>in-depth one on one interviews</u> and analysis of existing public opinion, was accompanied by the results of a commissioned national survey of voters.

This document summarizes those learnings.







The initiative is designed to strategically include several types of activities that are tall to provide a comprehensive picture of people's needs, including:	king place simultaneously
Commissioned research to learn even more about people's values, needs, desire policy solutions.	ed outcomes, and
Regular analysis of public opinion to ground our findings in the wealth of existic commissioned by national leaders and to monitor shifts in the landscape. Topline shared with state and federal policymakers.	· ·
In-depth interviews and ethnographic conversations where we have open di and small groups.	alogue with individuals
	and external advisors,

How People are Engaging with the Health Care System and the Barriers Preventing Them From Getting the Care They Need

Many peoples' engagement with the health care system is tainted by negative experiences and overwhelming concerns about the cost of care and the inability to depend on their coverage.

- The cost of health care is the most prominent concern and dominates the discussion across all of the listening activities we've undertaken, which is consistent with previous research.
- The struggle to pay for health care is consistent, with many patients reporting that they are all too familiar with the variety of ways they are faced with cost, from premiums to co-pays, to prescription drugs, and hospital care.
- Anxiety related to what many patients view as an intentionally complex and confusing system, especially related
 to insurance policies. They express fears that being unable to navigate the system would lead to unexpected bills and
 personal medical debt. One patient put it like this: "Been feeling crappy and I finally made an appointment to see a
 doctor. It's sad that I'm so paralyzed by the complexity of my insurance and medical systems that I'd rather suffer."
- People are forced to spend a great deal of time figuring out their own coverage and finding providers that meet their
 needs. While few people seem content with their health care, they often feel they have better care than others because
 of the time and effort they put into researching it, and because of specific factors, including but not limited to being
 computer literate, speaking english, or being able to advocate for themselves.
- There is an increasing concern about the fact that the coverage they've put extensive time and energy into figuring out is not dependable. There is also concern that they could easily lose it through changes in employment, age, and health status, among other reasons.
- A significant distrust and anxiety in the system broadly. This includes distrust in the media's reporting of medical
 research, the role of pharmaceutical and insurance companies, and the belief that many doctors are motivated primarily
 by profit.
- We found that while health care impacts all of us, only a small percentage of the public is engaged in the health care policy conversation. Many people are turned off by the partisan discussions and completely disengaged. Those who are engaged in the policy debate tend to approach it from emotionally-charged, partisan corners. Many people are vigilant for partisan "trigger" words—such as "access" on the left and "government control" on the right.

We pivoted during the pandemic to understand shared, and important differences, people have in how they are feeling and what needs they have.

Common Concerns, Worries, and Needs Related to the Pandemic

While there are some nuances to the responses, we found that the following shared needs generally cut across demographics and geography.

- Concerns and worries tend to break into three clusters: 1/ health; 2/ death or dying; and 3/ money, the economy, and bills.
- Our national survey found that people are feeling a mix of emotions related to the pandemic, and that those emotions are overwhelmingly negative. Most notably, **respondents feel concerned (53%), anxious (47%), uncertain (44%), and frustrated (35%).** However, people are also finding hope (33%) in the midst of crisis in religion, their families, and stories of people helping others.
- Some of the responses around money were rooted in job security and the potential to lose a job as a result of the pandemic.
- The vast majority of worries related to protecting and providing for loved ones rather than respondents themselves. We also found an increased concern for the health and wellbeing of neighbors and community members.
- We also found broad desire to address the following four critical shared needs:
 - » A reliable health care system that is fully resourced to support essential workers and available when it is needed, both now and after the pandemic.
 - » A health care system that cares for everyone, including people who are vulnerable and those who were already struggling before the pandemic hit.
 - » Accurate information and clear recommendations on the virus and how to stay healthy and safe.
 - » Being able to provide for ourselves and our loved ones, especially as we are worried about the financial impact of the pandemic.

Building Toward a New Vision for the Future of Health Care

The pandemic has amplified inequities and disparities that have existed within our health care system for far too long. People believe that we must emerge from the coronavirus pandemic stronger than before and this presents us with an opportunity for real reform. Our research has illuminated the public's interest in building toward a system that is centered around people rather than politics or the health care industry; a system in which:

- **People have certainty that they can afford their health care.** Cost is a critical barrier to access for far too many Americans. People want to know that they can afford the care they receive and that they won't have to choose between their health and potential bankruptcy.
- People have the security and freedom that dependable health care coverage provides as life changes. Regardless of life's changes—whether they lose their job, grow their family, or move to a new state—people want to know that they will have dependable, accessible health care coverage.
- People can get the personalized care they need, when and how they need it. People want to be able to access care when they need it, and have their care tailored to their individual needs. This could include telehealth, convenience care, or simply having a hospital nearby. It also includes addressing the deep inequities that exist in our system, holistic care, and mental health.
- **People experience a health care system that's understandable and easy to navigate**. Complexity is overwhelming, and people want to be able to understand and navigate the system.

Our Findings Actively Inform USofCare's Strategy and Approach

USofCare has already begun integrating these findings into our resources and policy recommendations. We have published a <u>Guide to Humanizing the Health Care Debate and COVID-19</u> for leaders across the country, as well as an accompanying resources on <u>Humanizing the Response to COVID-19 by Listening to People</u>. Our listening efforts were also central to informing our <u>federal</u> and <u>state</u> policy responses to the pandemic, and are guiding our strategic vision for the future of health care.

Ensuring People's Shared and Different Needs Guide Health Care Improvements is Paramount

USofCare is working to shift the dynamic to center real people in the national health care conversation. This is difficult work, and USofC has utilized the findings of our research to identify commonalities and differences in the needs of people across the country. As a result of this national research and deep listening with those most impacted, we know that policymakers must:

- Acknowledge that the existing system is flawed and work to remove the barriers that prevent people from getting the
 care they need.
- Ensure people are at the center of the process to develop policy by listening to constituents and formalizing the ways input is gathered from community members and business leaders.
- Pay close attention to extensive research pointing to disparate health outcomes among specific groups of people. Ensure that policies are written in a way that addresses those disparities.
- As potential policies are being considered, recognize the interconnectivity between health and financial wellbeing and promote solutions that reduce health care costs while making coverage dependable.
- Recognize that health care policy has a very real and personal impact on individuals. People want to see concrete actions that address the anxiety and fears that accompany personal health care experiences.

Prioritizing Solutions Based on the Needs of People, Not the System Itself

Our research over the course of the past year has helped identify and refine our vision for the future of the health care system, including the four specific areas outlined in the Emerging from the Pandemic Stronger section above, where people want to see change, and where we hope to make a difference.

Through our comprehensive approach and deep listening, USofCare aims to elevate people's needs to ensure that several key areas are explicitly acknowledged and addressed in future solutions and priorities. Those areas include supporting policies that reduce the cost of health care, make coverage more dependable, and increase the level of personalized care while maintaining quality across the system.



United States of Care is committed to working closely with our cross-sector partners and policymakers to improve the health care system by paving a path to durable, people-centered policies.

Learn more at **USOFCARE.ORG**

