



Understanding People's Health Care Priorities

This publication is meant to guide health care industry understanding and application of the most common individual health care priorities.

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Introduction

In the evolving landscape of health care, understanding and prioritizing people's needs and preferences is crucial for the system to effectively promote and protect the health of the entire population. The health care experience is deeply personal and also significantly shaped by people's economic and social context. Diverse individual experiences and contexts require health care ecosystem organizations like health plans, systems, and providers to proactively work to understand each person's health needs and priorities and be nimble enough to tailor care plans to a wide variety of health and health care needs.

However, in navigating the health care ecosystem, patients and caregivers often find that health care institutions and practices prioritize the organization's convenience and business practices above what people seeking care need. [Research shows](#) that people hold a relatively high level of distrust in the U.S. health care system, and decreased trust is strongly associated with worsening self-reported health.

Issues like 1) [escalating costs](#), (including [lack of transparency](#) about costs), 2) [complexities](#) of the health care ecosystem that make it difficult to navigate, and 3) concern that health care institutions do not prioritize people's interests above organization interests, contribute to growing dissatisfaction with and mistrust of health plans and provider institutions. Promoting a clear understanding of people's health care needs and priorities is essential to improving health care delivery and enabling payment transformation.

Addressing the disconnect between what people prioritize, value, and need in health care and what the health care ecosystem currently provides is key to defining and implementing practices that advance and protect the health and wellbeing of all people. This chasm, known as '[goal discordance](#)' in clinical settings, can lead to increased costs, poorer quality, and further mistrust and inequities. By collaboratively structuring and delivering services that are centered on people's health care priorities and preferences, health insurers, systems, and providers can develop solutions that meet the goals of the individual and ultimately increase engagement and improve outcomes. Understanding people's health care priorities and preferences can positively impact multiple dimensions of individual and community health care, including:

HCPLAN Person Perspectives Council

The HCPLAN launched the Person Perspectives Council in late 2023 to champion and promote people's lived experience in the health care system as it relates to the advancement of alternative payment models and value-based care. Council members serve as powerful voices driving their individual missions and increasing the focus on person-centeredness within the HCPLAN and the industry overall.

Current council membership includes representatives from four organizations:

- [Community Catalyst](#)
- [FamiliesUSA](#)
- [National Partnership for Women & Families](#)
- [PFCCpartners](#)

Introduction

- **Agency and Autonomy**

Addressing the factors that limit people's health and health care options and impede their ability to make informed, autonomous decisions about their health will increase trust, self-efficacy, and ultimately, strengthen engagement and information sharing to improve outcomes. Shared decision-making is an essential component of this, including making space for self-advocacy.

- **Equitable Access to and Quality of Care**

Focusing on each person's specific needs and priorities within their social context demands understanding how structural factors, such as systemic racism, gender bias, geography, among others, impact people's health risks, health related social needs, and ability to access respectful, high quality care at the right time. Tailoring care plans to address and/or mitigate specific barriers to better health will improve health outcomes, reduce disparities and promote fairness in the health care system.

- **Enhanced Trust and Relationships**

Navigating the US health care ecosystem requires managing complex financial transactions and controls that can interfere with the relational aspects necessary to establish and nurture trust with clinicians. Investing in building longitudinal relationships where the individual's needs, priorities, and values are openly communicated helps build trust, and enables more transparent and frequent dialogue that informs collaboratively developed care plans and improved [outcomes](#).

- **Better Health Outcomes**

Tailoring care to the specific needs and preferences of individuals, while ensuring systems are designed to address their social and economic contexts, can support people and remove barriers to advance and protect people's health. This includes facilitating preventive care and managing chronic conditions, which leads to better health outcomes and enhanced well-being. This requires systemic changes to provide access to what people need, prefer, and value.

- **Improved Wellbeing**

Aligning health care services with people's priorities and preferences enhances people's overall quality of life. This includes not only physical health, but also emotional and psychological well-being.

Objectives of this Guidance

This guidance joins previously-published guidance, such as US of Care's [United Solutions for Care](#), to provide a foundation for understanding the priority factors that are important to people when seeking health care; this document aims to:

- **Inform**

Provide health plans and provider organizations with a clearer understanding of the many dimensions of needs that influence what people prioritize when seeking health care services.*

- **Align Services**

Offer actionable insights on how to engage in person-centered redesign to align offerings and services with people's needs and expectations.

*This document uses lived experience and preferred terminology according to people and patient advocacy experts; a glossary of key terms is included in the Appendix.

Introduction

- **Enhance Satisfaction**

Suggest strategies to improve people's satisfaction with their health care through targeted improvements in affordability, access, and experience.

The business of health care in this country wields enormous power compared to individuals and communities and could be much more intentional about wielding it in ways that protect and enhance everyone's health. A strong focus on what people say they need and want from the health care system is needed. These findings on person-centered health care priorities can assist entities like health plans, providers, and provider organizations in better achieving a more nuanced understanding of patients' needs and preferences to improve health outcomes and patient experience in the US. Operationalizing principles can also enhance health organization programmatic and financial strength needed to build healthier communities. Applying the insights of people with lived experience is a critical first step towards adopting practices that improve health outcomes through increased dignity, trust, respect, and ultimately, quality of life.

Priority Assessment Approach

Priority Assessment Approach

The HCPLAN Person Perspectives Council began by conducting an extensive landscape analysis. This analysis included a literature review of academic articles related to people's preferences and priorities in health care decision making, and an evaluation of 22 tools and resources that provide value ratings for health plans, institutional providers, and individual health care practitioners. The synthesized findings and evaluation of the existing resources¹ were then developed into initial priority dimension findings.

To validate and expand the findings of the landscape analysis, the HCPLAN Person Perspectives Council held numerous qualitative interviews with leaders and experts from health care organizations that advocate for patients and caregivers.² Interviews occurred between June 2024 and August 2024 with the goal of representing the voice of the individual person into the resulting priority dimensions.

The council used open-ended interview questions to explore individual priorities across the domains of health coverage, health service organizations, and individual health care providers. Representatives provided input to refine proposed priority dimensions, identify priorities among specific factors, comment on emerging trends in health care that may affect people's priorities, and address other topics relevant to their organization and personal expertise.

Analysis Findings

Prominent literature incorrectly frames people's experiences in health care as one of being a "consumer": Many academic articles reflect the industry's treatment of people as 'consumers' and refer to people as such. Stakeholder interviews revealed how this framing of people as 'consumers' is incorrect since patients do not have the choices and consumer leverage available in other industries.

People face constrained options and systemic barriers in making optimal health care decisions: Academic literature suggests that individuals often struggle with suboptimal health care decisions due to limited information, systemic barriers, and the complexity of health care systems. This framing unfairly places the burden on individuals by assuming they have full autonomy and access to all necessary resources. Instead, stakeholder interviews revealed that people's lived experiences are that they have suboptimal health choices. Health plans and providers must be accountable for and to patients and communities by offering clear information and transparency, thereby providing the comprehensive and person-centered support and resources needed to make well-informed decisions and receive improved care.

¹ See Appendix B for complete listing of references

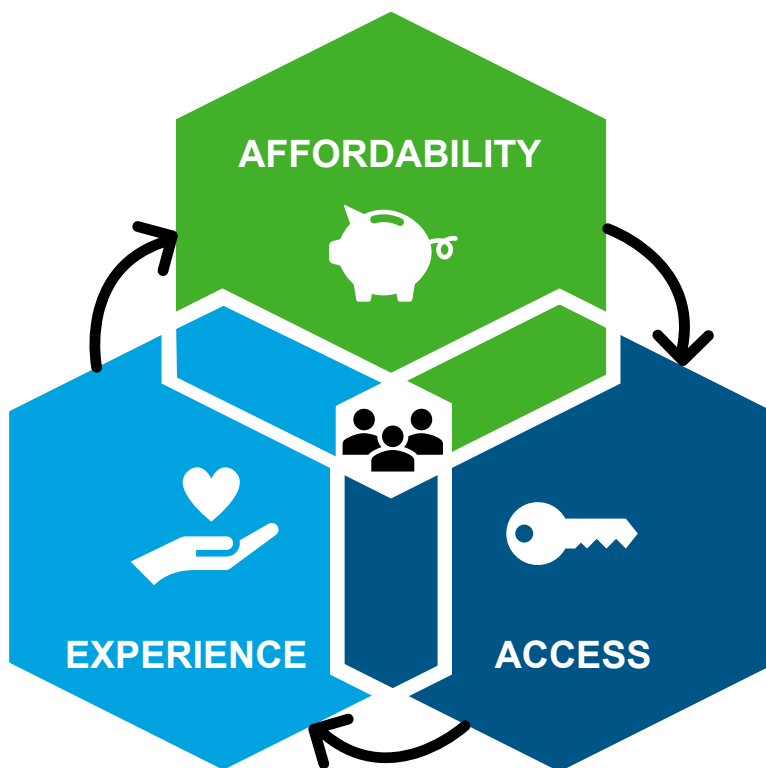
² In addition to organizations represented by the HCPLAN Person Perspectives Council, patient advocacy organizations interviewed include the Camden Coalition, Grapevine Health, the Patient Advocate Foundation, Medicare Rights Center, National Council on Aging, Justice in Aging, US of Care, and the National Urban League, and CMS experts on Medicare, Medicaid, Marketplace programs

Person-Centered Health Care Priorities Findings

Person-Centered Health Care Priorities Findings

The landscape analysis and stakeholder interviews informed the identification of top priorities comprised of three dimensions and prioritized factors. Findings and related insights serve to increase health care stakeholder awareness and competency of the primary dimensions that people prioritize in their health care and the relationship between them.

Figure 1: Person Centered Health Care Priorities



Priority Dimensions

Findings reflect some of the priorities people have for their health care based on their lived experiences, individual needs, and community context. Priorities are nuanced and vary based on an individual's cumulative personal and family experiences with their health and interacting with the health care system. These priorities can be organized in three core areas that embody the collective concerns of many people, along with some foundational needs of individuals that are less heard. Featured priorities are not comprehensive or a rigid inventory; they represent the areas that people prioritize most based on the current health care ecosystem and environment. In addition, these dimensions can overlap and influence each other.

Person-Centered Health Care Priorities Findings

Factor	Description	Examples	Significance
Affordability	Alignment between the cost of receiving the health care people need and individual's available resources	<p>Direct costs of health care:</p> <ul style="list-style-type: none"> • Health insurance premiums • Out-of-pocket costs: co-pays, co-insurance, and deductibles • Costs for the full range of health care services, including prescription drugs <p>Indirect costs of health care:</p> <ul style="list-style-type: none"> • Transportation • Opportunity costs <p>Key affordability influencers</p> <ul style="list-style-type: none"> • Economic disparities* 	<p>People prioritize affordability because it is the gateway to accessing care at all, and thus governs their ability to access care and receive high quality experiences</p> <p>*Health Equity Insights Racial and ethnic minority groups often face economic disparities that limit their ability to afford health insurance and health care services. For instance, Black and Latinx adults are more likely to be uninsured compared to their white counterparts. This lack of insurance can prevent them from accessing necessary medical care. Additionally, the legacy of redlining has perpetuated these disparities by restricting access to capital and investment in minority communities, leading to lower property values, higher poverty rates, and reduced economic mobility. These systemic barriers contribute to the ongoing challenges in achieving equitable health care access.</p>
Access	The ability to gain entry to and receive health care services. In addition to being affordable, care must be available and people must be able to reach care	<ul style="list-style-type: none"> • Insurance provider network • Appointment availability • Wait times to get an appointment • Wait times during appointments • Health care workforce shortages* • Extended hours • Telehealth options • Office locations and proximity / distance to providers • Transportation availability • Language services 	<p>People prioritize access because without it they cannot effectively obtain the care they need, when they need it, and the quality experiences required for optimal health outcomes</p> <p>*Health Equity Insights Predominantly Black and Latinx communities are more likely to experience shortages of primary care physicians and health care facilities. This means that even if individuals can afford care, they may not have access to it due to a lack of available providers in their area.</p>
Experience	The quality and satisfaction of people's interactions with the health care system. Being treated with respect and fairness is at its foundation, as is being able to easily get their specific health care needs met. Experience encompasses the full breadth of the health care journey	<p>Subjective factors:</p> <ul style="list-style-type: none"> • Clear and respectful communication • Trustworthiness • Responsiveness • Cultural humility • Efficiency <p>Objective factors:</p> <ul style="list-style-type: none"> • Safety • Clinical quality • Care coordination • Discrimination in health care settings* 	<p>People prioritize experience because the challenges of interacting with our complex and fragmented health care system can be a huge barrier to getting their health and health care needs met, which impacts their well-being, comfort, and safety in the context of their health care and in their broader life</p> <p>*Health Equity Insights Racial discrimination within health care settings can lead to suboptimal care and mistrust of the health care system. This can result in delayed or avoided medical treatment, which can exacerbate health issues and lead to higher health care costs over time. For example, patients who do not speak English fluently may receive inadequate care due to communication issues. This can result in misunderstandings about symptoms, treatment plans, and follow-up care.</p>

Person-Centered Health Care Priorities Findings

Priority Dimension Interactions

Priority dimensions are connected and often intersectional in the context of a person's life; findings depict how dimensions build on each other, the ways dimensions influence each other, and how those interactions materialize in people's lived experiences.

- **Affordability and Access**

Reliable health care access does not exist without affordability. Even the broadest provider network can still be inaccessible when the cost of receiving care exceeds the person's available resources.

- **Access and Experience**

Beyond accessing health care generally, people prioritize how they are treated in the pursuit of obtaining high-quality care. For example, the experiences of securing an appointment, interacting with their clinician, engaging in treatment, having questions answered, etc. can either enhance or detract from the overall health care experience, including the ability to get their health care needs met.

- **Experience and Affordability**

These interdependent priorities directly affect a person's ability to obtain the care they need. The experience of doing what is needed to keep care affordable, such as navigating provider networks, drug formularies, pre-authorizations, and surprise out-of-network charges, can be overwhelming and dissuade people from seeking and obtaining the care they need.

These dimensions act as a series of hurdles people must overcome in order to maintain and improve their health; the ultimate outcomes are not achievable unless health care organizations prioritize equity in all three elements. In an ideal state, the intersection of these three dimensions upholds a health system that functions equitably for the people it serves. Each dimension—affordability, access, and experience—must be enhanced with a focus on equity to reach the ideal future state. Together, optimal and equitable affordability, access, and experience yield a person-centered approach to delivering health care. This approach is essential to strengthen health outcomes for individuals and communities, and to improve overall quality of life for all.

Priority Factors:

- The figure on page 12 displays factors that people prioritize most across the three dimensions of affordability, access, and experience. Specific factors pertain to one of three domain categories: health coverage, health service organizations, and individual providers, with several factors that can apply to more than one domain category.
- This list is not meant to be exhaustive, but rather feature areas that people prioritize among these dimensions and domain categories according to the current assessment.

Person-Centered Health Care Priorities Insights




Priority dimensions and specific factors are interdependent and complementary. There is no singular factor that stands out as most important, but instead a sequence of key priorities that collectively unlock favorable health experiences and outcomes. Health care stakeholder support of priorities and fundamental determinants like equity are also required to achieve optimal health outcomes. What people prioritize and the extent that people can navigate health care according to their priorities relies on how well health coverage and care provider services accommodate people's cross-dimensional needs.

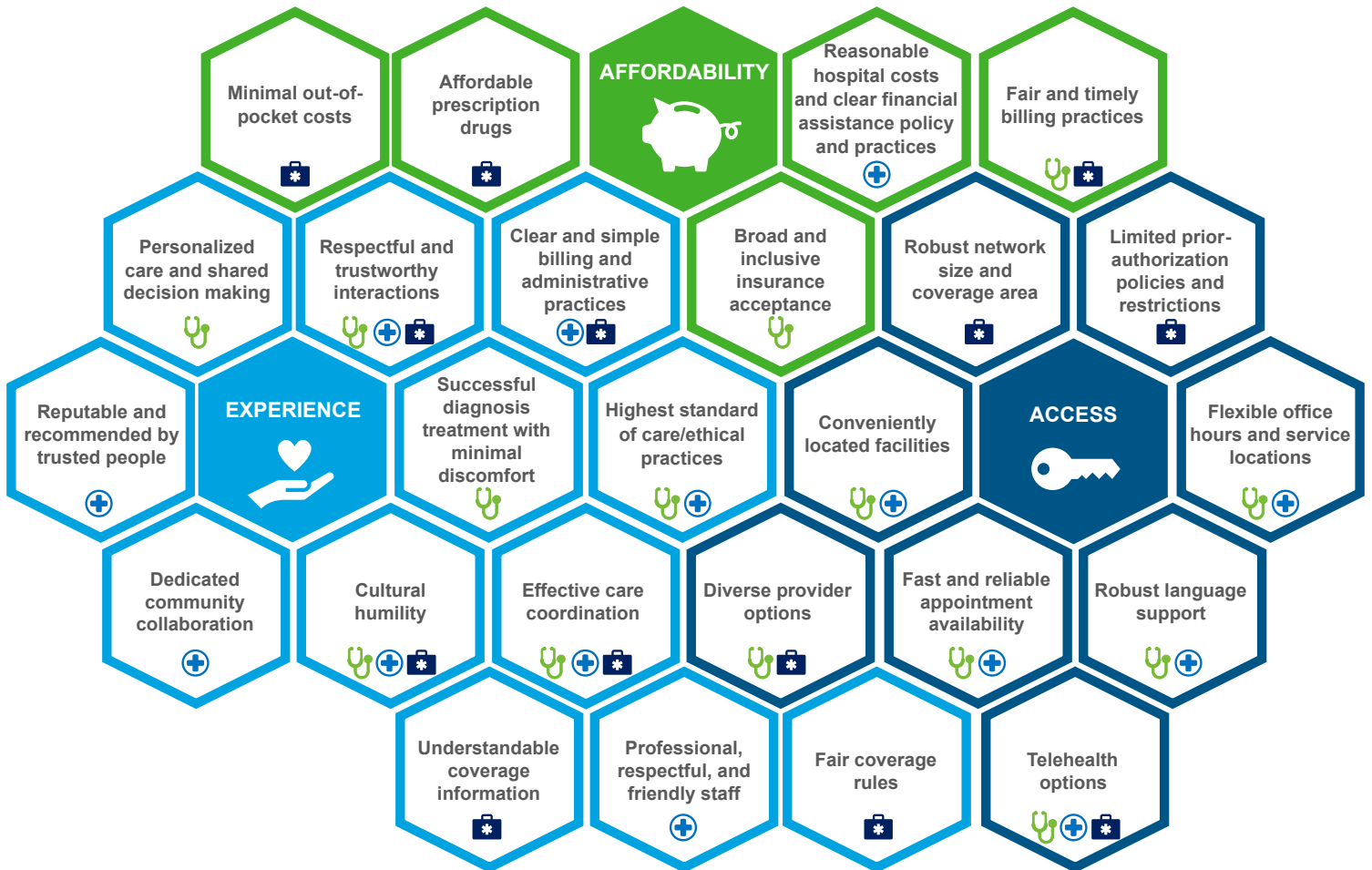
Person-Centered Health Care Priorities Findings

Figure 2: Factors People Prioritize When Seeking Health Care

Key: Health Care Domain

Health system **stakeholder groups accountable for factors** and components that uphold dimensions

-  Health Coverage / Insurance
-  Health Service Organization
-  Individual Health Care Provider



Person-Centered Health Care Priorities Findings

Affordability

Insights on Challenges

While people's emphasis on affordability may be well known, current views and specific aspirations for health care affordability reinforce the need for long-lasting solutions. Interviews with patient advocacy organizations corroborate the prevalent and urgent need for lower costs.

The burden of high costs

- Patients and caregivers face certain unavoidable and often unpredictable health care needs, but the high costs associated with these should be avoidable. Out-of-pocket costs are especially burdensome and unjustified, leaving many frustrated by having to pay extra for necessary services on top of paying for their health coverage.
- People are often surprised by cost sharing amounts they must pay for routine services; they attribute the issue to faulty and ambiguous policies as well as excessive underlying costs.
- Beyond out-of-pocket costs, patients and caregivers also face opportunity costs when seeking care, whether it be the costs of travel to appointments or lost wages.
- Opportunity costs further financially burden people seeking care, particularly those with limited income and/or resources. For example, people in hourly jobs forfeit pay to be at a medical appointment. When provider systems are inefficient, patients shoulder the burden of reduced income.

Fairness in cost ownership

- Similarly, people are experiencing major sticker shock from the cost of prescription drugs. They do not believe the high prices are warranted and find it unjust that people paying for vital medicines appear to be funding a very lucrative pharmaceutical industry.
- On the other hand, Medicaid beneficiaries that should have limited out-of-pocket obligations encounter facilities and providers that do not accept their coverage and are thus left to either pay the full amount (if they even can) or simply forego care until it becomes an emergency. This often leads to burdensome medical debt, exacerbating economic disparities.

Transparency does not equal affordability

- While there is appreciation for transparency, price disclosure efforts do not enable people to overcome cost hurdles to receiving the care they need. Transparency may encourage health plans and providers to focus on delivering better quality services over high volumes and profitable prices, however people need attainable costs above all.

"We live one health care crisis away from bankruptcy."

– PFAnetwork member

Person-Centered Health Care Priorities Findings

What Affordability Means to People

Figure two displays people's top priorities related to affordability. People need minimal to zero out-of-pocket costs and affordable prescription drugs from health plans. From health service organizations and individual providers, people prioritize stable, low, and predictable costs, along with clearly explained and comprehensive financial assistance policies and practices. They also expect inclusive (non-discriminatory) insurance acceptance and fair billing practices to ensure that health care expenses do not become an undue burden among their other financial obligations and are left with crippling medical debt.

The steep expenses people face in the current system create situations where vulnerable people are deciding whether to incur debt to pursue medical treatment, offset health care expenses by forfeiting payment for other needs such as safe housing, or avoid the cost by not seeking needed treatment. With medical debt being the [primary cause](#) of bankruptcy for families in the U.S., it is clear that these precarious options are the reality for many people. There is a well-known link between health and financial well-being: those with [financial stress](#) are more likely to experience poorer health overall, while those with [higher incomes](#) have lower likelihood of illness and premature death. Further multi-stakeholder alignment and adoption of practices that expand affordability for patients is required to correct this disparity – the PPC and LAN are examining how this can be done within various domains.

Access

Insights on Challenges

There is a common misconception that convenience is not a requirement for basic health care. Evaluation of people's priorities related to health care accessibility reveals consensus around the need for standard accommodations. Concerningly, "convenience" factors like provider location and hours are often treated as a luxury rather than integral to health care. The consequences of inaccessibility are less about the 'inconvenience' of trying to receive care, and more from the harm caused by systemic interference to prompt and consistent care, especially for low-income and structurally marginalized communities. While it may be tempting to write-off major access barriers to stubborn social and economic root causes, health organizations can and must play a large part in expanding their own reach so that every person can access health care, no matter where they live, where they work, their income, or primary language.

"Access to health care should be a right, not a privilege to those that can afford it."

– PPC member

Person-Centered Health Care Priorities Findings

Interviewees described everyday accessibility barriers that people face, including: hospitals and doctors located far away from some communities requiring costly and burdensome travel, non-English-speaking patients and caretakers having to navigate care with minimal interpretation services, and people facing several month wait-times to see specialty providers and PCPs despite their appearing to be many options. Barriers restrict people's ability to obtain both routine and critical care: market consolidation, insufficient health care resources, geographic disparities, limited operating hours, workforce shortages, complex and burdensome administrative practices for patients and providers. When presented with these obstacles, people are forced to resort to disruptive and often costly alternatives, including:

- **Travel to far away locations** to see in-network, available providers
- **Going self-pay** to see an out of network provider that is immediately available
- **Pursuing alternative care in retail clinics and urgent care providers** that are not equipped to handle complex or chronic conditions that require ongoing care from a primary care provider; continuity of care issues are exacerbated when EHRs block timely and accurate information sharing across providers and include the patient and family caregivers.
- **Not pursuing or delaying care;** provider office hours overlapping with the typical workday deters people that cannot afford the missed pay or are disrupted from their workdays and commitments

Interviews also indicated prior authorization as a common challenge people face when trying to access care. Restrictive policies and arduous practices cause delays in care, administrative burden, patient frustration, inequitable access per the disproportionate impact on underserved and minority populations, and even increased costs due to the need for additional administrative support and delays in care that lead to more severe health issues, and ultimately worsening health [outcomes](#). Overuse of authorization policies create access obstacles for people and conflict with accountable care progress.

What Access Means to People

Easily available health care services: People care most about the availability of providers and the effort required to reach them. Additionally, people prioritize dependable, flexible, affordable and non-restrictive health care options. In practice, this means reliably available appointments supported by adequate network sizes and coverage areas, flexible office hours and service locations (including telehealth services), and non-restrictive prior-authorization policies that do not limit people's ability to receive timely treatment.

Diverse provider options: People also prioritize who provides their care, with people of color and LGBTQI+ people especially wanting diverse provider options and cultural congruence. These [preferences](#) are supported by research findings that a diverse health care workforce helps expand health care access for the underserved and close gaps on inequities that lead to health outcome disparities for minority communities. [Various research](#) has shown that race and ethnicity concordance between patients and physicians leads to [more effective care](#) and better health outcomes.

Person-Centered Health Care Priorities Findings

Language support: Similarly, the needs of people with limited English proficiency must be recognized. All interviewees underscored that language support services remain a priority for many patients and caretakers. First, the robust availability of high-quality interpretation and translation services is crucial and must be financially and logistically supported. In addition, more facets of the health care system must mirror the racial, ethnic, and gender diversity of communities, and where possible be located within those communities. Promising practices that promote a diverse health care workforce involve social, academic, and financial support [programs](#).

Experience

Insight on Challenges

Patient experience directly influences people's health outcomes. Failure to provide a respectful, positive experience reduces health care effectiveness, places care further out of reach when overly complex systems become impenetrable, and at worst, endanger the lives of patients when lack of respect and cultural humility lead to mishandling and care quality [failures](#).

There is unsettling evidence of these more extreme health risks. Research shows that people of color have higher rates of hospital acquired infections, health complications, dosing errors, and adverse drug events compared to white people, and determinants like interactions with health care professionals, patient engagement, and language proficiency coinciding with higher risk of patient safety incidents among minority [populations](#). An often cited example of quality and experience disparities leading to poor health outcomes is black patients' [experiences](#) with pain relief in health care settings, particularly from white providers. [Studies](#) as late as 2016 found alarming rates of provider and medical trainee held biases and false beliefs about Black people being less sensitive to pain, fueling inadequate and negligent treatment of Black patient's self-reported pain.

“We need to center health care on the lived experience and not treat patients like consumers.”

— Sinsi Hernández-Cancio, National Partnership for Women & Families, PPC Council Member

Person-Centered Health Care Priorities Findings

What Experience Means to People

Experience has several components, so it is useful to further segment this broad dimension into three facets. Together these capture the quality of interaction and care that people receive from providers and health plans, and there are priorities across sub-categories that each entity is accountable for satisfying.

Trust, respect, and cultural humility

Priorities related to trust, respect, and cultural humility apply mostly to individual providers and health service organizations. Health plan fairness, namely non-discriminatory coverage rules, was indicated as a notable priority as well. People prioritize health institution collaboration and engagement with their community along with favorable patient satisfaction and credibility according to trusted sources. For individual providers, being treated with respect and establishing and continuously nurturing trust are paramount, though people appreciate provider reputation particularly when recommended from family or friends. Beyond these foundational factors, patients and caregivers prioritize personalized care and shared decision making, key practices within person-centered care. This subset of experience can be improved by clinicians, provider institutions, and health plans establishing themselves as trustworthy, striving for cultural humility, and expanded partnership with community-based organizations to achieve community cohesion.

A simpler system and robust navigation

The U.S. health care system is famously complex and fragmented, so it is to be expected that a common theme connecting system navigation priorities is simplicity. People prefer straightforward health plan administrative processes and well explained coverage information from insurers, along with provider billing practices that are simple and well defined. Many interviewees explained how most people are not versed on the intricacies of health care operations and financing, and emphasized that navigating the system should not require that expertise. [Research has demonstrated](#) that over exposure to information and system complexities can negatively impact experience by distracting people from their primary goal, maintaining their health. Furthermore, complexities that create challenges for patients reflects the industry's lack of respect for people. Treating people with dignity requires the system to acknowledge the impact of every health care process on people and building norms with that sensitivity in mind. To that end, health care entities should consider opportunities to center simplicity for those navigating the system and ensuring that the service components people find obscure or inconvenient are understandable and easy.

Quality of care that reflects what people need

Health care quality can have an entirely different meaning to people than it does to industry practitioners; this gap must be addressed to make real progress towards broad quality improvement and patient priority realization. People prioritize high care standards and ethics, effective care coordination, and successful treatment with minimal discomfort, however there is opportunity for more effective methods to understand provider performance in these areas. Health plans and providers can better align experience measures with patient priorities by including Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) in their value-based care contracts.

Person-Centered Health Care Priorities Findings

Like simplicity, the quality of health care interactions suggests the respect the system has for individuals and frames their experience. For example, entities adopting all electronic communications without regard for older people's capability or preferences is an action that lacks person-centeredness and could imply a lack of respect. There is a need for greater focus on quality factors that patients care about the most and aligning what people expect around quality and experience with industry standards and delivery. Lastly, while quality performance is driven by providers, health plans can advance patient experience through functional supports like race, ethnicity, and language (REL) and health disparity data collection and sharing.

Foundational Elements that Support Priority Dimensions

Interviewees and literature also indicated that certain foundational factors must serve as a baseline in order for the priority dimensions to be fully realized. Foundational elements uphold priority dimensions and help sustain a functioning system. Various far-reaching supports help the system function for people; the most emphasized in interviews and relevant to current gaps are health equity (fairness & justice), choice (though an elusive for many), and understandability (clarity). Where certain priority factors are difficult to affect, health organizations must continue improvement efforts in these far-reaching areas.

- **Health Equity:** The attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address inequalities, historical and contemporary injustices— which includes systemic racism— and the elimination of health and health care disparities. (via HEAT and adapted from Healthy People 2030)
- **Choice Illusion:** The right, power, and opportunity to make decisions about medical care and having options to choose from to exercise that right. Genuine choice also requires having options to choose from. However, many individuals, particularly those in specific geographical areas, with limited income, Medicaid beneficiaries, racial/ethnic minorities, individuals with disabilities, LGBTQI+ individuals, immigrants, and those with limited English proficiency, face constrained or nonexistent options. The classic notion of autonomy emphasizes the importance of individuals having the capacity to make informed decisions. However, this capacity is rendered moot if the environment constrains the available choices.
- **Understandability:** Addressing system overcomplexity by ensuring that information is clear, accessible, and culturally proficient. Health systems must prioritize making health care environments less complex and more adaptable; this approach reduces the demands on patients and helps them to effectively navigate and utilize health services This involves adhering to and strengthening of National CLAS Standards, the Plain Language Act, Title VI of the Civil Rights Act of 1964, Section 504 of the Rehabilitation Act of 1973, Title IX of the Education Amendments of 1972, the Age Discrimination Act of 1975, and Section 1557 of the ACA.

The Disconnect Between the Industry Today and People's Priorities

The Disconnect Between the Industry Today and People's Priorities

Through assessment of priority dimensions and individual factors, the PPC has identified common sentiments and themes that people hold regarding their health care and about the industry as a whole:

- 1. Health care costs need to be distributed more fairly to alleviate burdens on people.** Many people have difficulty managing health care payments among other financial obligations and feel that too much of the cost burden is falling on people in need of care. This is especially true for out-of-pocket and prescription drug costs; people are unable to afford the cost of care and do not understand why there are such significant cost obligations beyond their regular health coverage contributions. Health industry activation of affordable care strategies is required to ensure health care for all.
- 2. Doctors and services must be placed within reach of more people.** People are unsatisfied by the limited health care options available, which too often require travel to distant locations, are offered during work hours, or are not available when people need them. At a minimum, these issues restrict people's ability to tailor their health care to their personal and lifestyle needs; at worst, people are unable to access critical services altogether. Integrating access enablers into health care models is essential to breaking down current barriers.
- 3. Experience standards and practices should be rooted in people's needs.** While there is general trust in health care providers, many people feel that the system does not account for their needs, does not always respect them, overlooks people's expectations regarding the quality of their care, and the impact of experiences on health outcomes. Health care entities must adopt programs that measure the quality of the care people receive as well as the quality of their experiences in receiving it.

Disconnects between what people need and prioritize in their health care and what the industry delivers contribute to the underutilization of available high-value health resources and overutilization of more expensive emergency care, exacerbate health and social inequities, and endanger people's wellbeing. Frank introspection around health organization motivation alignment with the priorities outlined in this assessment must occur to identify existing gaps and eventually develop solutions to provide what people prioritize, for population health prosperity and the fortitude of the health care system. The HCPLAN and Person Perspective Council urge health care leaders to accept these priorities as what people need and adopt them into organizational planning and implementation. Organizations can start by taking the following actions:

- **Embrace people's priorities** – deepen your understanding and support organizational recognition of people's health care priorities. Hold listening sessions with the people you serve to enhance your understanding of their unique needs.
- **Understand your population** – gain insights into your specific patient population's needs to tailor application of priorities (e.g., requesting language preference in pre-service questionnaires, translation resources for administrative and clinical staff, etc.).
- **Reflect on alignment** – are these priorities embedded in the health plan or program design? Is there infrastructure in place to support alignment? Include people as design contributors by hearing from the people you serve about how they see these priorities reflected, or not, in the health plan and program design (e.g., compare current goals and tactical plans to priority factors then, pursue plans that are mutually beneficial).
- **Commit to continuous improvement** – add accountability to these priorities to organizational infrastructure and use tools to help elicit people's priorities (e.g., shared decision-making, care coordination advancement, etc.).

Appendix A: Lived Experience Terminology

Appendix A: Lived Experience Terminology

Industry Term	Person-Centered Term	Insight
Consumer	Person with lived experience	Referring to individuals as ‘consumers’ is misleading, as people seeking health care services lack the options and bargaining power that are present in other industries. The phrase ‘person with lived experience’ is preferred to words that disconnect the human experience, such as ‘consumer’ and in some contexts, ‘patient.’
Equity	Fairness & Justice (with respect to barriers, circumstances, and conditions)	‘Equity’ is conflated with financial meaning (e.g., home equity) and equality (conceptually where everyone gets the same rather than what they need), which can be confusing to the public. ³
Choice	Available options	Choice is defined as the right, power, or opportunity to choose among options; however, patients rarely have the luxury of choice. Options are placed before people to select from; options are fixed and choices are not.

³ US of Care, “The Health Equity Landscape From the People’s Perspective: 4 Key Insights from USofCare’s Listening Work” February 6, 2023 <https://unitedstatesofcare.org/united-states-of-care-releases-the-health-equity-landscape-from-the-peoples-perspective-4-key-insights-from-usofcares-listening-work/>

Appendix B: References



Academic Articles and Resources

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