



**The Beryl Institute -  
Ipsos PX Pulse  
Consumer  
Perspectives on  
Patient Experience  
in the U.S.**

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THE BERYL  
INSTITUTE



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# INTRODUCTION

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This report represents the 16th release of The Beryl Institute – Ipsos PX Pulse as we continue to explore the core trends impacting healthcare and the human experience in the United States (U.S.).

In this edition of PX Pulse, our key tracking measures remain steady with some slight—but interesting—trends. Notably, perceptions of quality in the U.S. healthcare system continue to lag, with fewer than 50% of respondents rating it as “Good” or “Very good.” At the same time, the importance of experience remains “Very important” or “Extremely important” to over 90% of the U.S. population.

The topics we explore deeper in this release include an awareness and understating of the Centers for Medicare and Medicaid Services (CMS) Hospital Star Rating System, a look at how patients seek to control and engage in their own care encounters (in collaboration with Society for Participatory Medicine), and a look at the role of caregivers in the U.S.—who does it, in what ways, and the challenges people face in taking on this responsibility.

This release of PX Pulse reflects a great cross-section of how consumers are informed by and engaged in the healthcare system. It seeks to understand challenges they face and desires they have. More than just understanding these issues, it urges us to consider what we can do to support healthcare organizations, patients, care partners, and communities in addressing obstacles and uncovering new opportunities for meaningful change.

That remains the greatest opportunity after each release of PX Pulse. Not simply to reveal what people say but provide insights that can inspire what we do about it. We hope the findings that follow not only shine a light on what is possible but inspire ideas that can help transform the human experience for all in healthcare.

# METHODOLOGY

This research was conducted using online surveys fielded through the Ipsos KnowledgePanel,<sup>®</sup> one of the only probability-based online panels that is representative of the U.S. population. The KnowledgePanel was chosen to provide one of the highest levels of accuracy and representativeness available on the web, allowing for the accurate measurement of consumer experiences, opinions and behaviors in the United States.

In total, 1031 completed surveys were obtained in the United States through the KnowledgePanel for this quarter's release. The survey was fielded from November 12 through November 20, 2024 to a sample group of people that were randomly selected to be representative of the U.S. population in terms of Census estimates of gender, age, race, ethnicity, education, income and region. The survey was fielded in English-only. Findings presented in this report were weighted to correct for any over- or under-representation in the distribution of completed surveys across these demographic categories, as well as to account for the aforementioned over-sampling.

Since the launch of PX Pulse in early 2020, we have presented findings that include a list of core items and deeper dive sets of questions. This quarter, our inquiry touches on perspectives and use of the U.S. CMS Hospital Star Rating System, exploration of patient perceptions of control of their care encounters, and a look at how people feel about the role of caregiver in healthcare today.

## The core questions we have asked since the launch of PX Pulse include:

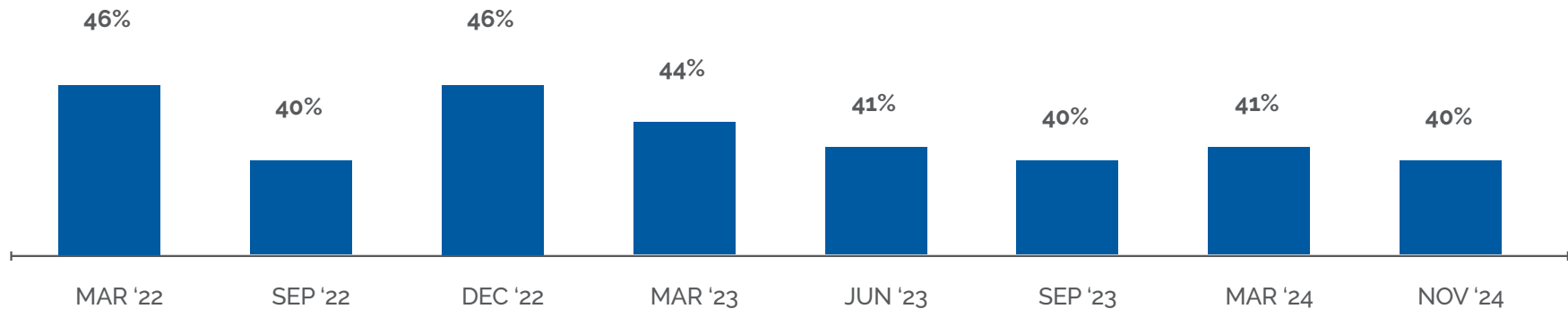
- 1 Thinking about the healthcare system in America as a whole, overall, how would you rate the quality of healthcare in this country?
- 2 From the following list, which healthcare issue is most important to you?
- 3 Thinking about how you have experienced healthcare in the past year, how would you rate your overall experience?
- 4 Overall, how important is it that you have a good patient experience?
- 5 Why is having a good patient experience important to you?

# CORE TRENDS

## Consumers' perception of quality is steady but still remains low.

The perception of the quality of the healthcare system in America has not changed significantly over the last year and a half (Figure 1). It remains substantially below the high point in our data collection, currently at 40% compared to a high of 46% two years ago. It should be noted that the perception of healthcare quality being "Very Good" or "Good" has not been above 50% since October 2021.

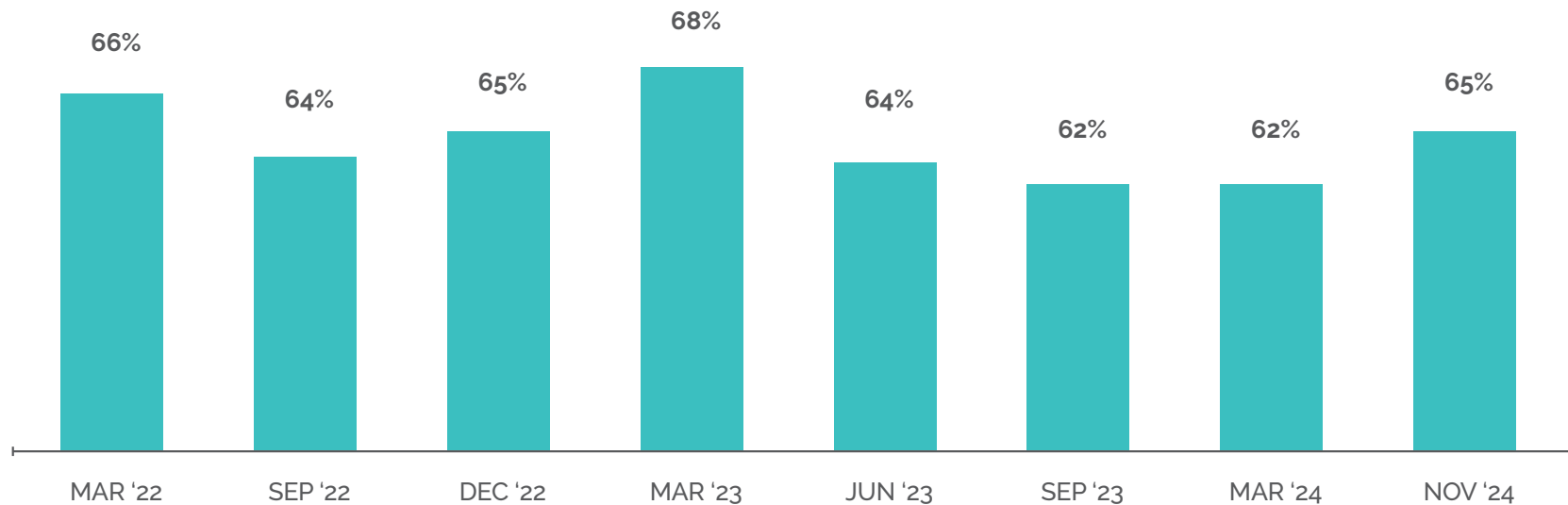
Figure 1. Quality of Healthcare in America (% "Very Good" + "Good")



## Consumer perception of overall care experience ticks up slightly while suggesting an opportunity for improvement.

While the perception of quality of the healthcare system remained flat, people's perception of their overall experience with the healthcare system climbed slightly to 65% (Figure 2). Over the last two years, this score has remained relatively unchanged. This data supports the continued commitment we see from organizations in their efforts to improve experience but reveals that still one in three Americans reflect their experience has not been good. An opportunity for improvement clearly remains.

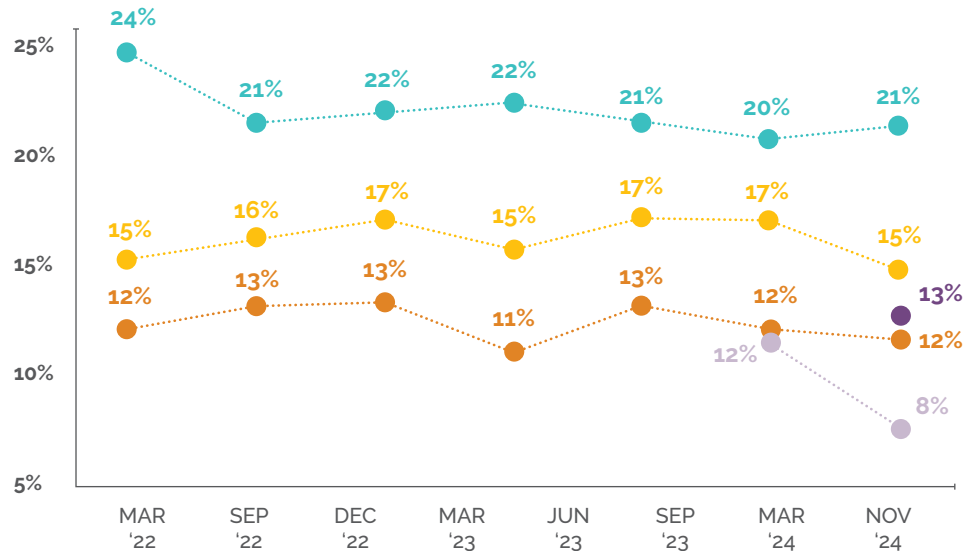
Figure 2. Overall Care Experience in the Past 12 Months (% "Very Good" + "Good")



## While cost continues to be important to the U.S. consumer, so is quality.

Similar to previous reports, cost-related issues remain top of mind. When asked about the single most important healthcare issue, “Having affordable insurance options” holds the most importance to people (Figure 3). “Out of pocket healthcare costs” and “Cost of health insurance premiums” also remain top issues this quarter (Figures 3 and 4). Of interest in this release of PX Pulse is the emergence of a new top item, “Quality of care provided by primary care providers and specialists,” which was just added as a response option in this most recent inquiry. This was the third most important item identified by people and reflects that, while cost remains critical to healthcare consumers, they are also expecting quality care (Figure 4).

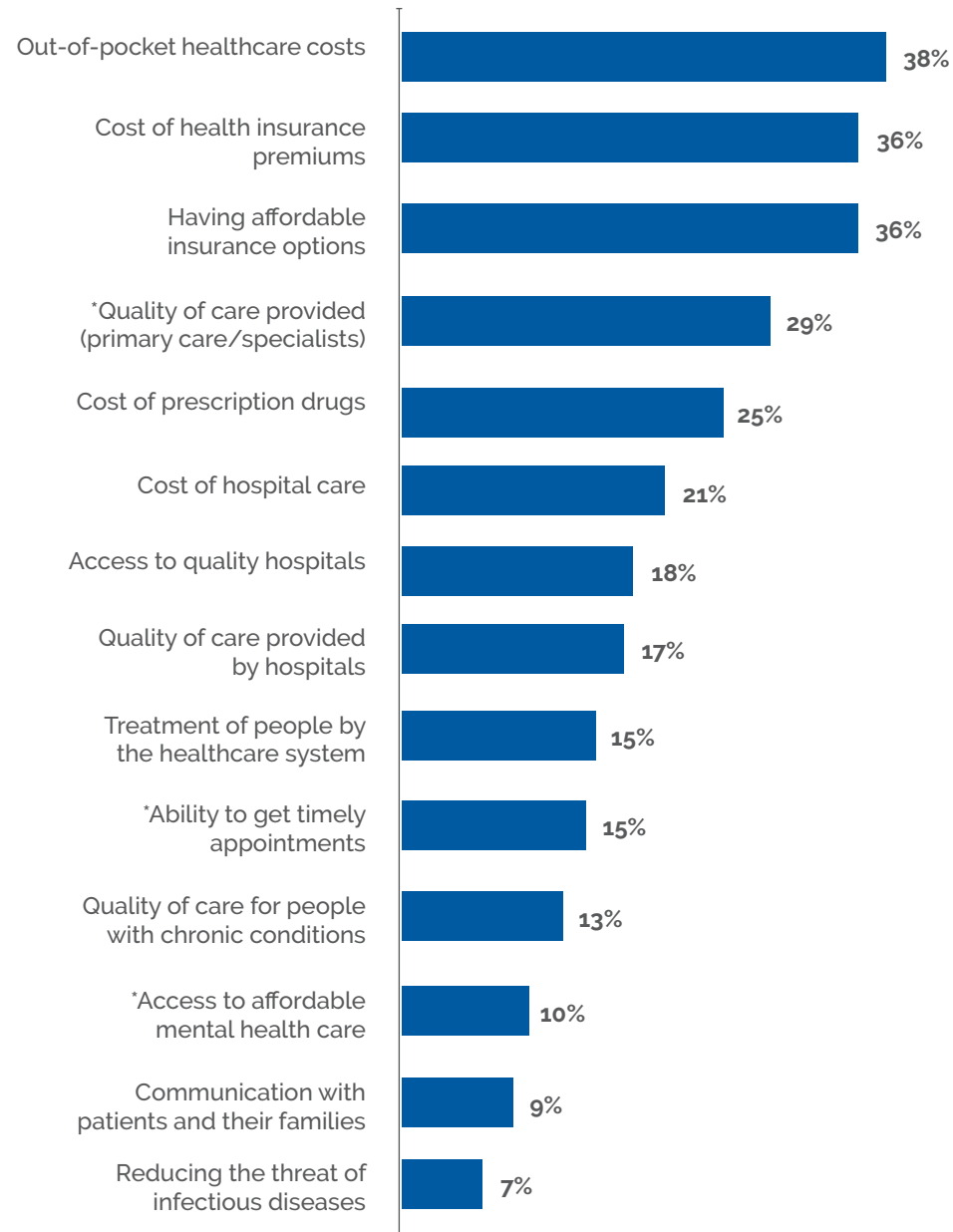
Figure 3. Which healthcare issue is most important to you? (Top 1)



- Having affordable insurance options
- Out-of-pocket healthcare costs
- Cost of health insurance premiums
- Quality of care provided by primary care providers or specialists
- Cost of hospital care

Note: Mar'24 this question was formatted as a ranking question, so Mar'24 is not included in this trend chart

**Figure 4. Which healthcare issues are most important to you? (Top 3)**

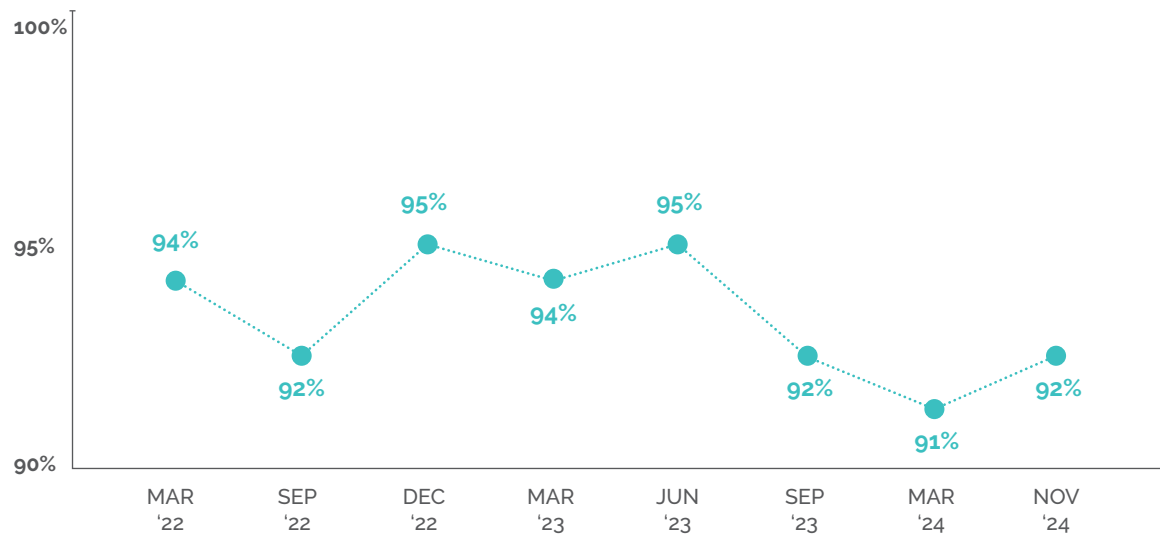


\*New response options added this quarter

## Importance of a good experience climbs slightly while people continue to reinforce that their health and well-being are important.

The number of consumers who think having a good experience is important ticked up slightly, with 92% of people thinking it is either extremely or very important (Figure 5). The top three reasons why people felt this way remained the same throughout 2024, including “My health and well-being are important to me,” “I want to know my physical needs are being taken seriously,” and “I want to be treated with respect” (Figure 6).

**Figure 5. Overall, how important is it that you have a good experience as a patient?**  
(% “Extremely important” or “Very important”)



**Figure 6. Why is having a good experience important to you?**

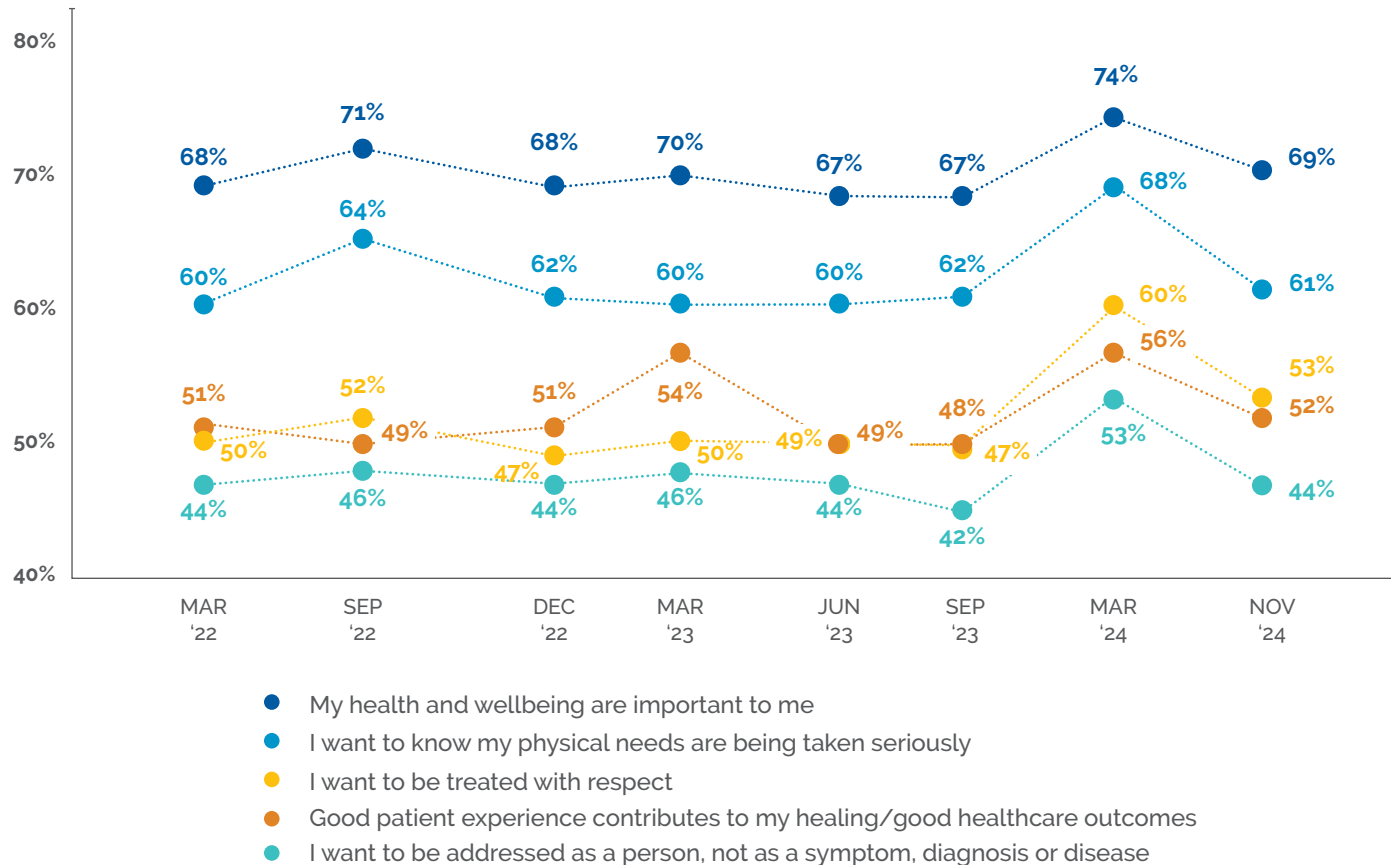
- 69%** My health and wellbeing are important to me
- 61%** I want to know my physical needs are being taken seriously
- 53%** I want to be treated with respect
- 52%** Good patient experience contributes to good healthcare outcomes
- 44%** I want to be addressed as a person, not as a symptom, diagnosis or disease
- 36%** It will influence how I make healthcare decisions in the future
- 36%** My time matters
- 33%** I am spending my money on this
- 17%** I see myself as a customer

## Consumers affirm the importance of personal health and well-being as central to their experience.

When asked why having a good experience is important to them (Figure 7), “My health and well-being are important to me” remained the top response for people. In fact, this has been the top response since PX Pulse first started in December 2019. Similarly, the second highest response in this release, “I want to know my physical needs are being taken seriously,” has remained in the second spot since the start of this inquiry.

In addition, the next two responses “Good patient experience contributes to good healthcare outcomes” and “I want to be treated with respect” have swapped the third and fourth slots for the entirety of our inquiry. This five-year trend highlights a consistent understanding of patient experience and its significance, making it impossible to ignore. Consumers may link experience to their health outcomes, as well as how they are treated. We must not make the mistake of trying to separate these efforts when striving to meet the totality of needs of those seeking care.

Figure 7. Why is having a good patient experience important to you?



# PX PULSE DEEP DIVES

In each release of PX Pulse, we explore key questions from the U.S. healthcare consumer. With this issue, we looked at three topics around how consumers understand and engage in healthcare. First is consumers' understanding and use of the Center for Medicare and Medicare Services (CMS) Hospital Star Rating System. Second, in collaboration with the Society for Participatory Medicine (S4PM), we looked at consumers' perspective of the control they want and engagement they have in their healthcare experiences. Lastly, we dug into how people experience the role of caregiver in the healthcare system today.

## Consumers know little about and almost never use Hospital Star Ratings.

The CMS Hospital Star Rating System is provided via the U.S. government with results posted on government websites that rate hospitals from one to five stars. This rating system allows people to compare hospitals across the country.

Our intent in asking about the Star Rating System was to understand if consumers were aware of this effort and the extent to which people used this resource. The findings were clear: almost 7 in 10 people have never even heard of this resource. Just 16% knew at least a little about it, and of that, only 3% reported knowing “a lot about it” (Figure 8).

When asking “How often do you use the hospital star rating system to make decisions about where to go for medical care?”—of the 31% who had at least heard of it, 41% reported that they never used the ratings at all (Figure 9). The implication of this finding is significant from both a policy and implementation standpoint. As hospitals seek to address these ratings and CMS continues to use these ratings for decision-making, there must be a greater effort overall to help consumers understand and engage in these measures.

Figure 8. How much did you know about this hospital star rating system?

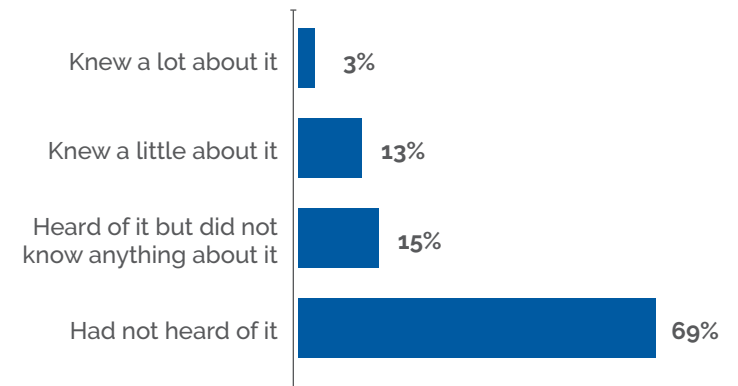
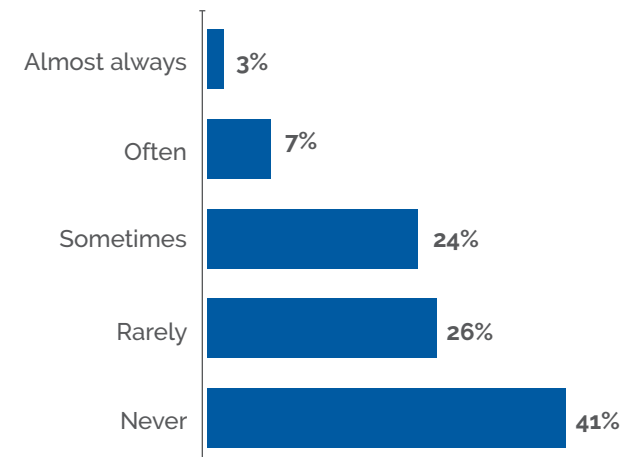


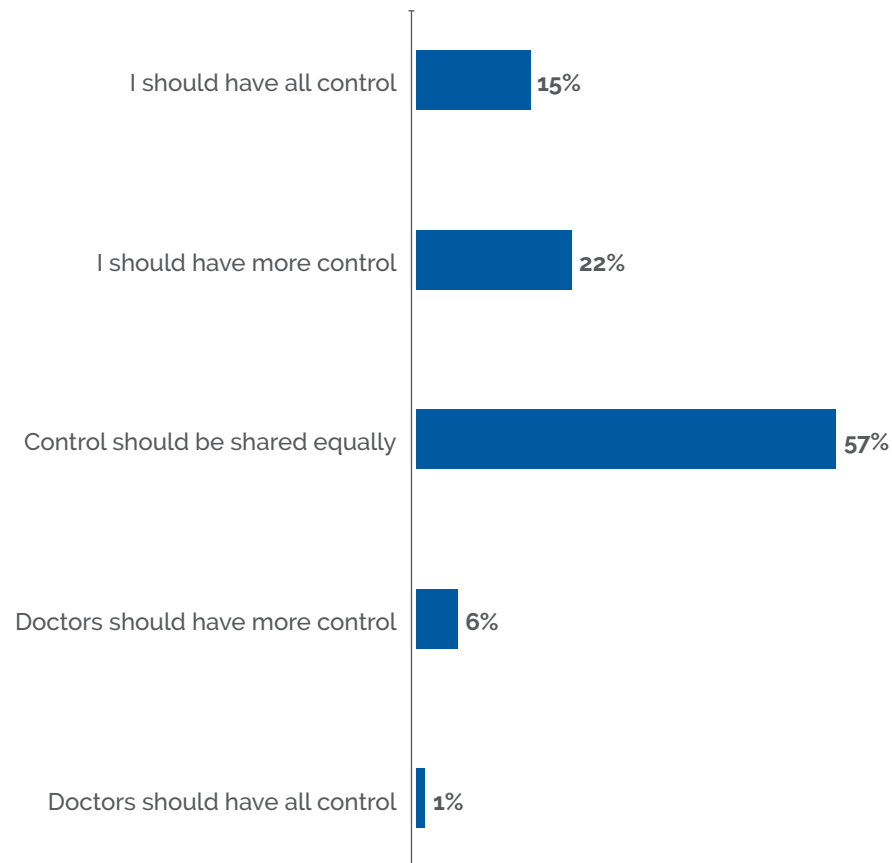
Figure 9. How often do you use the hospital star rating system to make decisions about where to go for medical care?



## Most consumers believe healthcare decisions should be shared between the patient and doctor.

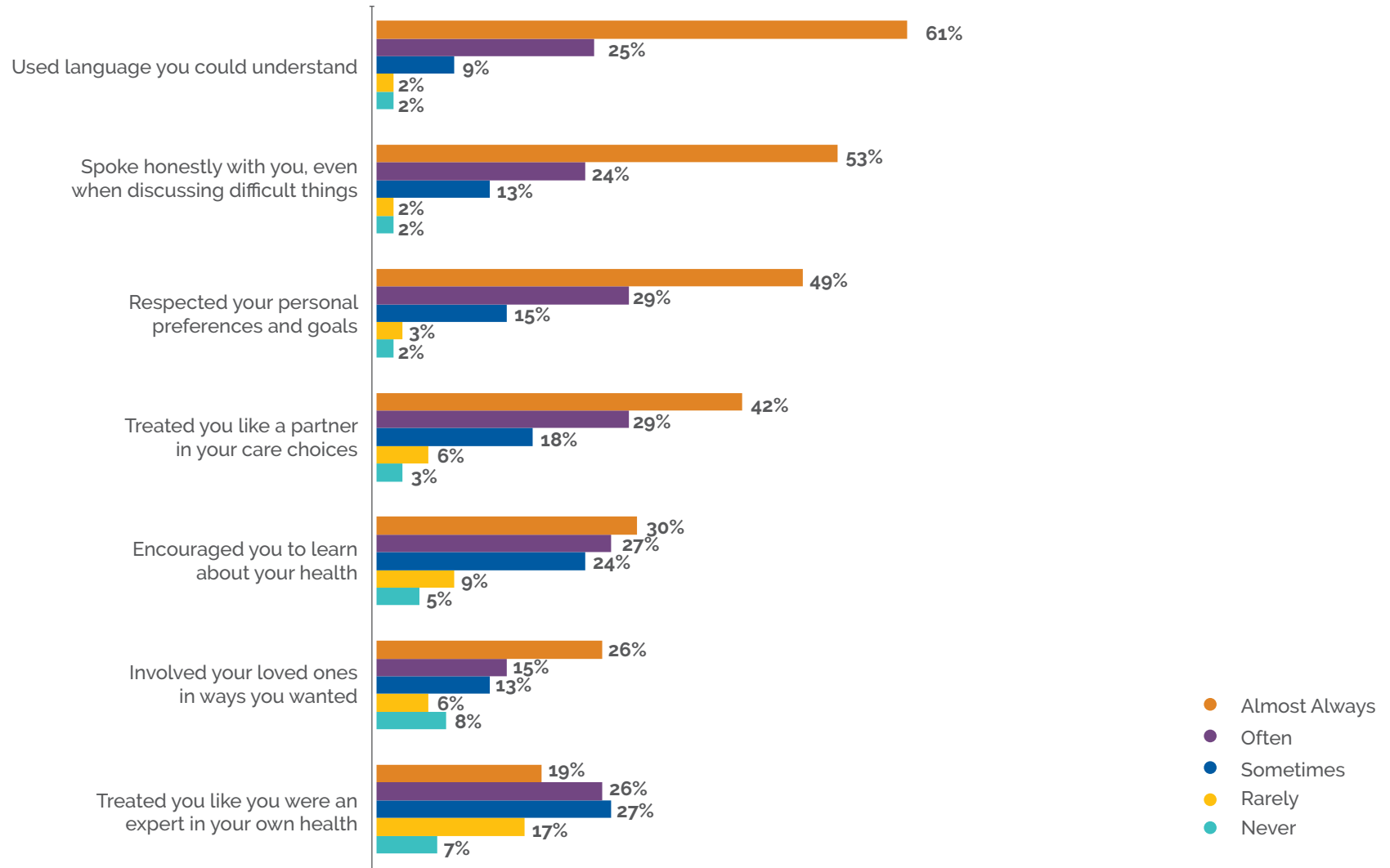
In collaboration with the Society for Participatory Medicine (S4PM), which is conducting a larger inquiry on this topic, we sought to understand how consumers view their engagement in care. In asking “Who should have control over healthcare decisions”—the majority (57%) said control should be shared between the patient and doctor. Only 7% reported that doctors should have “more” (6%) or “all” (1%) control, while 37% said they personally should have “more” (22%) or “all” (15%) control as the patient. The fundamental case for ensuring patient participation is clear with the majority of consumers seeking balance in decision-making (Figure 10).

Figure 10. Which statement best matches your own beliefs on who should control your healthcare decisions?



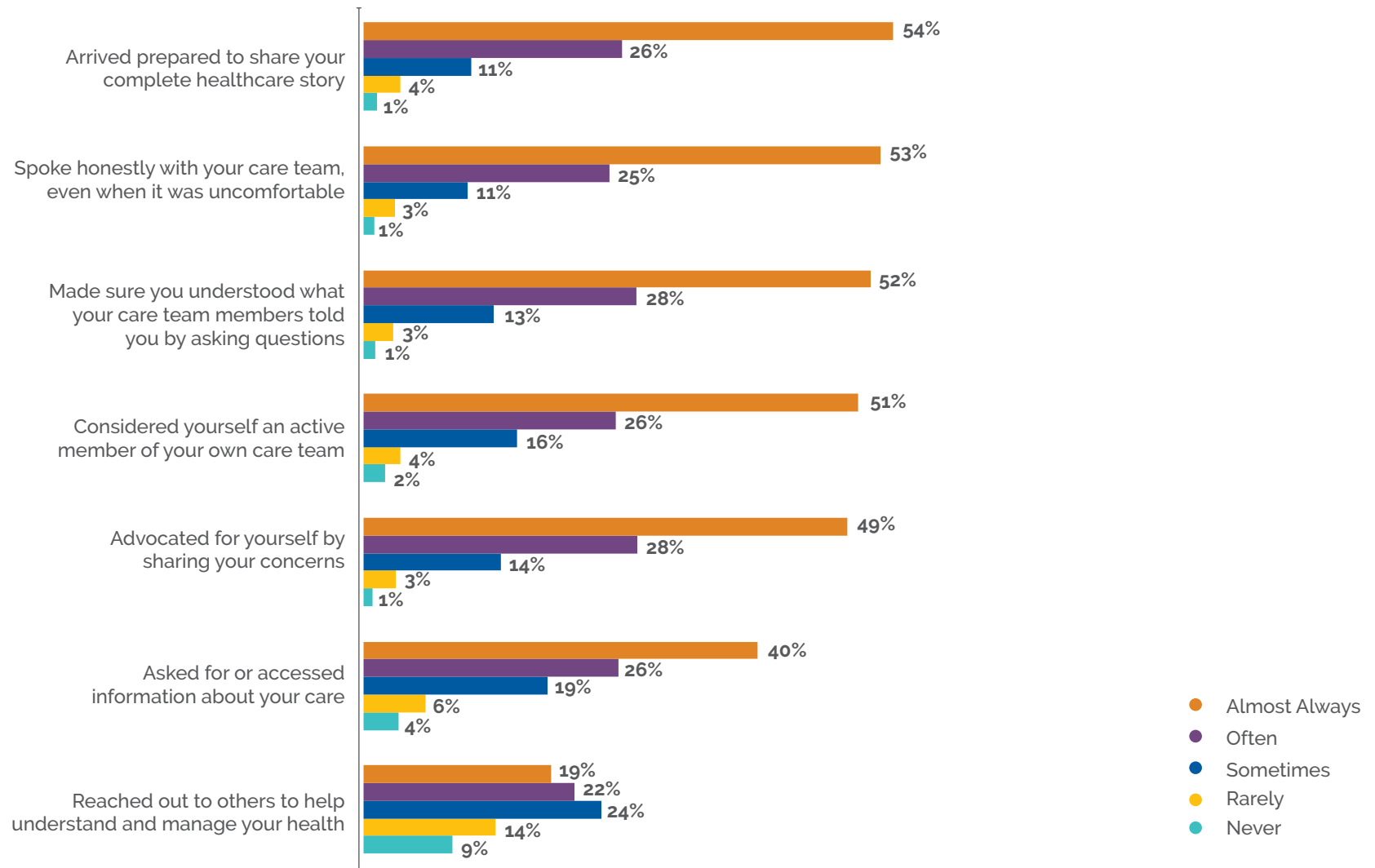
In asking consumers about their healthcare experience—specifically, “How often did your healthcare team members do the following?”—we saw a great alignment with what we learned from our 2024 consumer study<sup>1</sup> about what consumers seek. In that study, people expressed a desire to be listened to and communicated to in ways they could understand. This current inquiry revealed that, in two instances, a majority of respondents believed these interactions were almost always happening. Specifically, 61% of people reported that healthcare team members almost always used language they could understand, and 53% reported that healthcare team members almost always spoke honestly with them, even when discussing difficult things. These are encouraging headlines in how people are being engaged in their care (Figure 11).

**Figure 11. Thinking about the healthcare you received in the last 12 months, how often did your healthcare team members do the following?**



In this collaborative inquiry, we also sought to understand how patients came prepared for their healthcare encounters. A majority of people (54%) reported they almost always arrived prepared to share their complete healthcare story; 53% spoke honestly with their care team, even when it was uncomfortable; 52% made sure they understood what their team members told them by asking questions; and 51% considered themselves an active member of their own care team. Just under half (49%) reported they almost always advocated for themselves by sharing their concerns. What the data reinforce is that efforts to engage people in their care should not be viewed as a one-way process, but rather as highly interactive opportunities in which patients want to participate (Figure 12).

**Figure 12. Thinking about the actions you have taken as a patient in the last 12 months, how often did you do the following?**



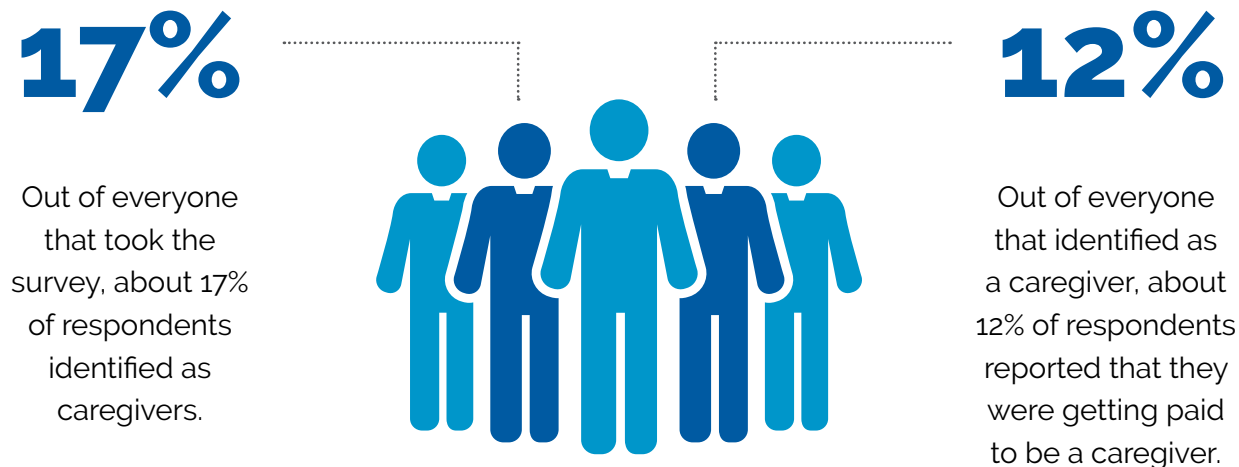
## Perspectives on Caregiving

In this release of PX Pulse, we looked more deeply at the concept of caregiving and the perspectives of and impact on those who see themselves as caregivers. For the purposes of this inquiry, we defined a caregiver as an individual who provides care and support to someone who needs assistance due to an illness, injury, disability, or aging. The care provided can range from companionship and emotional support to help with daily tasks. People who are considered caregivers can include family members, friends, or paid professionals. The responses below reflect all who identified as being a caregiver for someone currently.

### Most of the caregiving respondents are unpaid.

Of all respondents to this survey, 17% identified as caregivers. Overall, 12% of all who noted being a caregiver said they were receiving compensation in some capacity to be a caregiver (Figure 13).

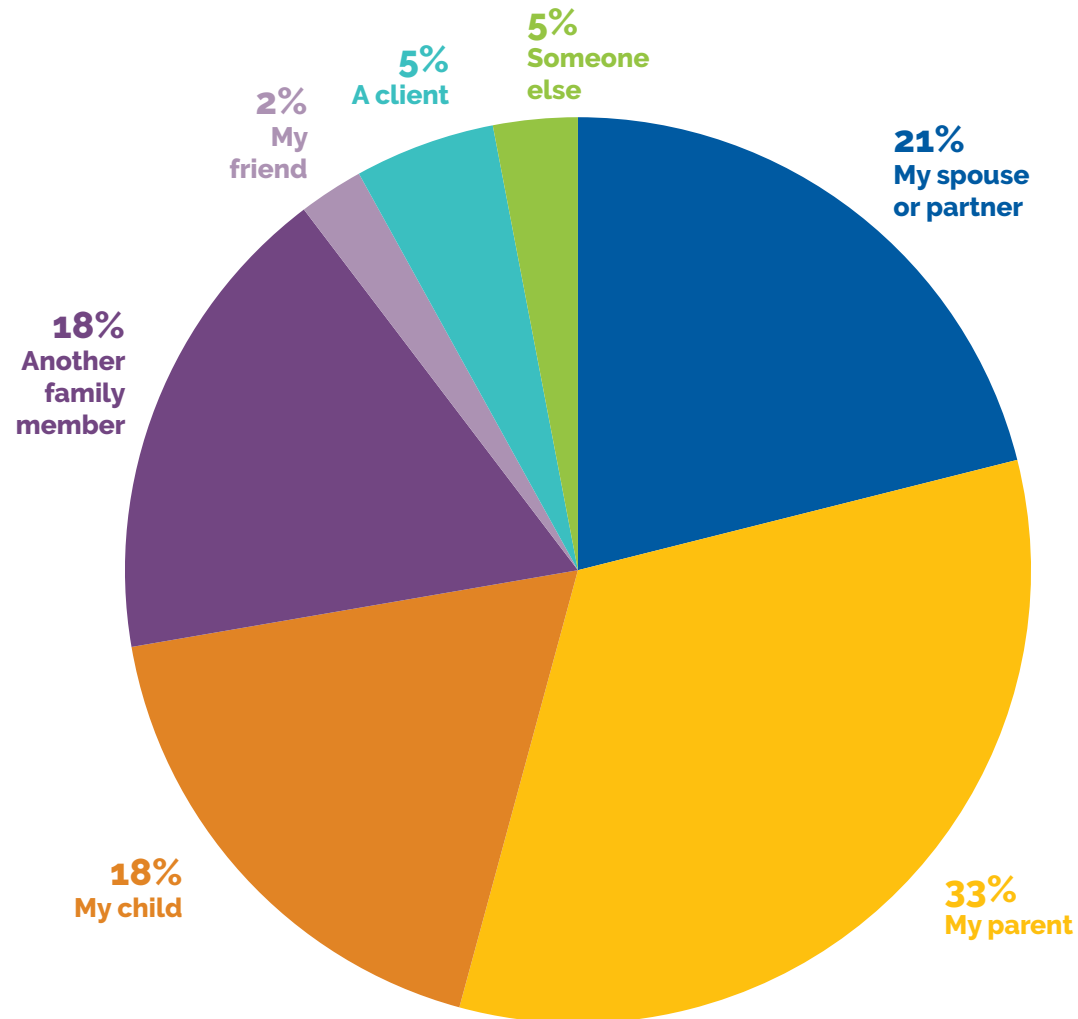
Figure 13. How long have you been a caregiver for this person?



## Most caregivers (89%) care for a family member.

Family caregiving was comprised of 33% caring for parents, 21% for a spouse or partner, 18% for a child, and another 18% for another family member. Only 5% of respondents noted doing this for a client. With nearly one in five people serving as caregivers, this highlights the significant burden individuals bear in today's healthcare system (Figure 14).

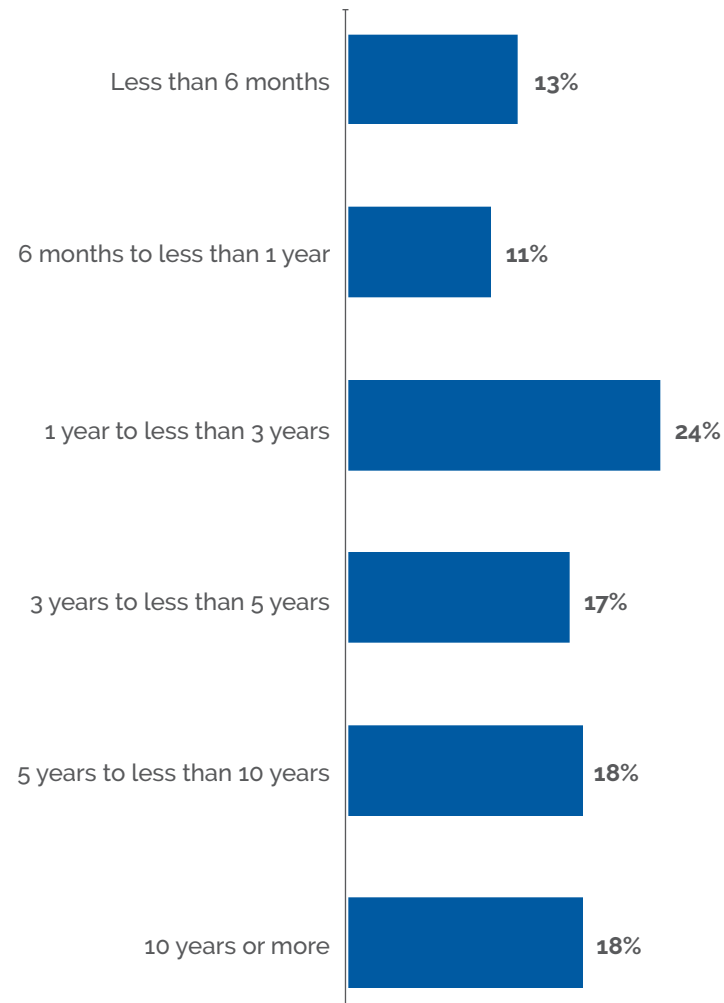
Figure 14. Who are you a caregiver for?



## People tend to be caregivers for extended periods of time.

The data reveals that caregiving is often a long-term commitment, with a majority (53%) of respondents providing care for three years or more and over a third of respondents for more than five years. In contrast, fewer than a quarter of respondents have been caregivers for less than one year (Figure 15).

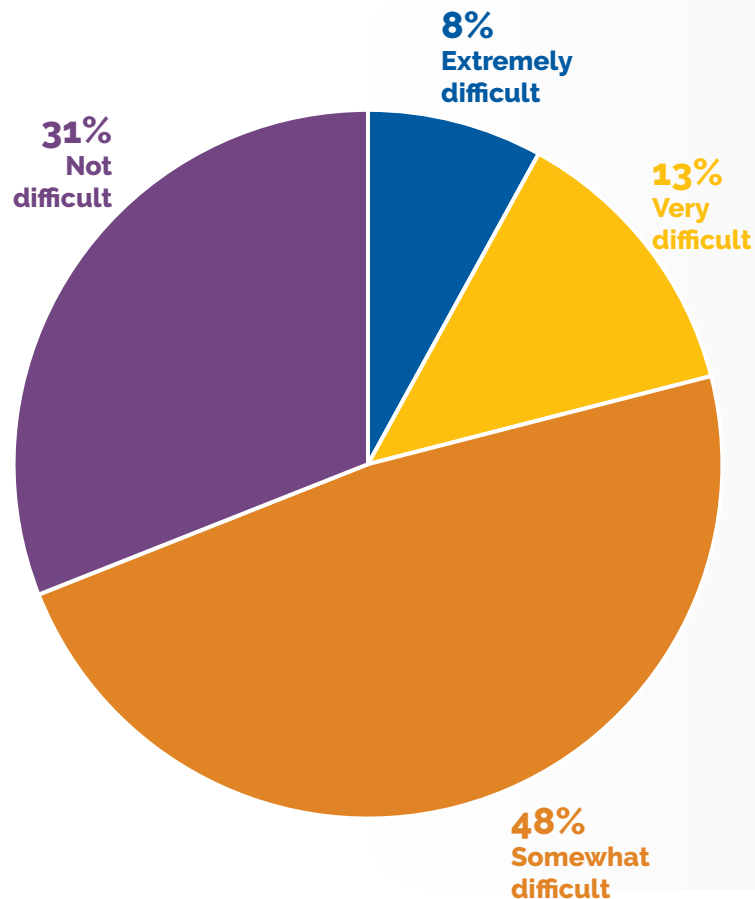
Figure 15. How long have you been a caregiver for this person?



## Most people have some difficulty navigating the healthcare system for the person they care for.

While about a third of caregiver respondents said they do not find it difficult to navigate the healthcare system, nearly half believe it is somewhat difficult, and about a fifth believe navigating the healthcare system is either extremely or very difficult. Some open comments highlighted challenges, such as confusion about insurance and Medicaid coverage, as well as a lack of a deeper understanding of the care recipient's needs (Figure 16).

Figure 16. How difficult is it for you to navigate the healthcare system for the person you care for?



### What makes it difficult for you to care for this person?

*"Much of the responsibility falls on me and sometimes I get overwhelmed with everything that needs to be done. I don't mean his personal care like bathing, dressing etc... I mean paying the bills, grocery shopping, doing chores around the house, etc..."*

*"Having to communicate with the person about their doctors' recommendations and making sure they follow through what is being told of them to do"*

*"I know little about Medicare and the system, and how to judge what makes someone else happy in healthcare. Also, I can't judge their patient experience."*

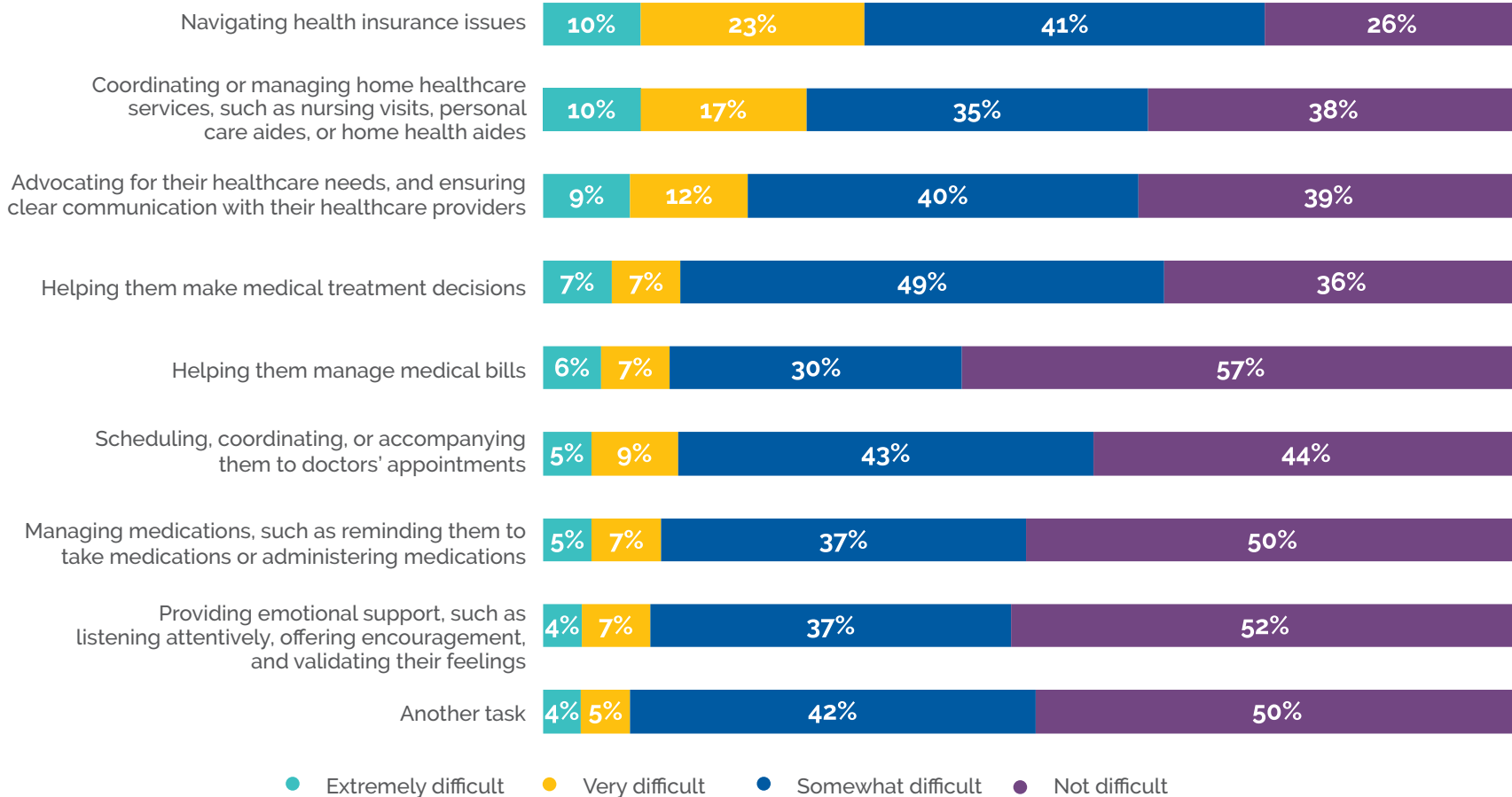
*"Insurance is the biggest block: it dictates which medications we can use, despite doctor's sense that s different medication would be of more benefit, and restricts access to certain radiology providers as well as land that the specialist may want."*



## Caregivers identify navigating health insurance issues as the most difficult task followed closely by coordinating care.

Navigating health insurance and coordinating care are among the most difficult tasks for caregivers. A third of caregivers report that navigating health insurance issues is very or extremely difficult, while over a quarter (27%) noted coordinating care was very or extremely difficult. The third most difficult task reported by just over 20% of all caregiver respondents was advocating for needs, which is also the third most performed task by caregivers. Notably, one of the top three primary tasks performed by caregivers is also one of the most difficult for them to take on. Additionally, the task that was not chosen as extremely or most difficult for them was providing emotional support, which could be due to the relationships that already exist between caregivers and the people they care for. The reality is the things caregivers are being asked to do are not easy tasks (Figure 18).

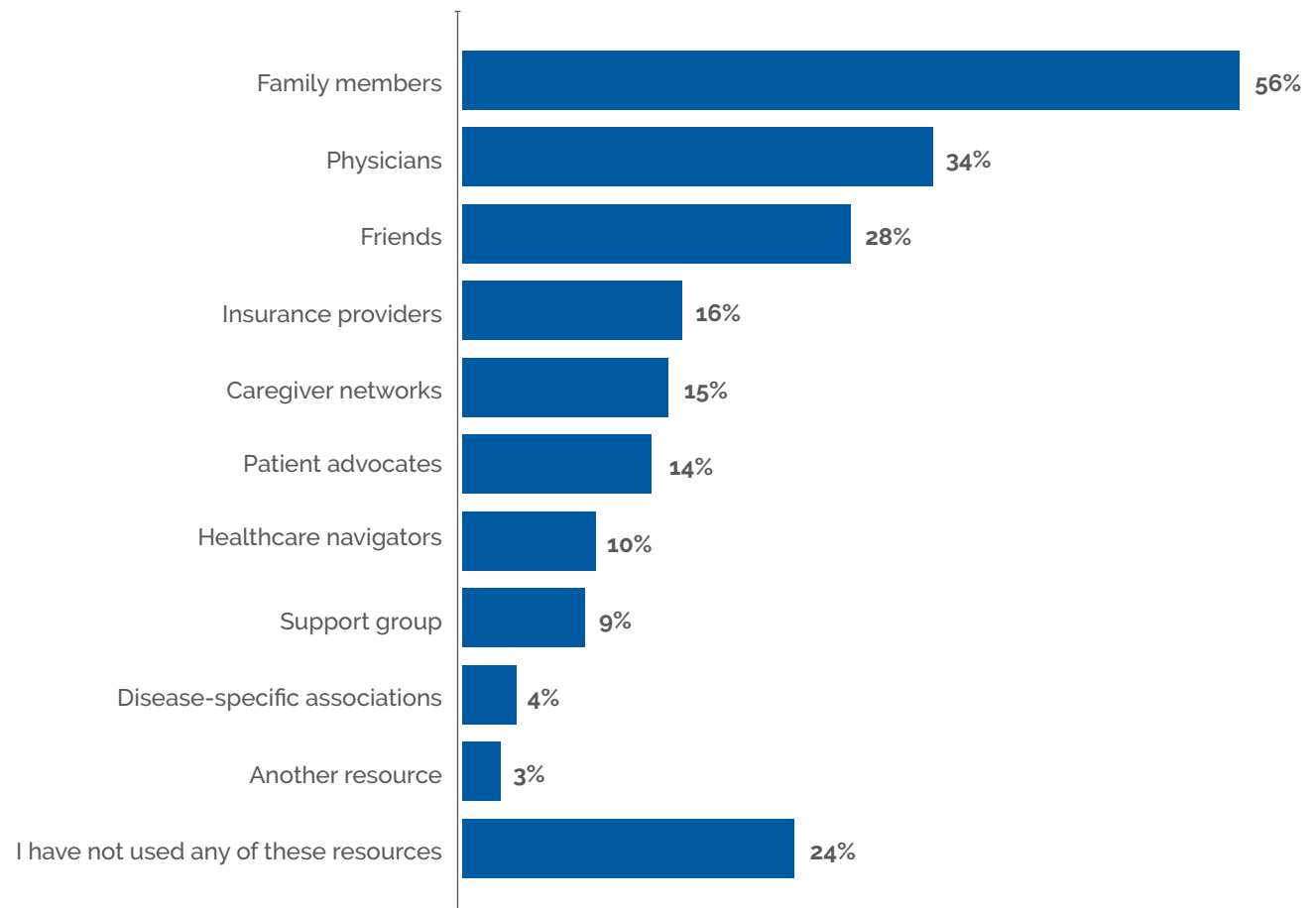
**Figure 18. How difficult are the following caregiving tasks?**



## Caregivers turn to other family members for help more than any other resource.

In asking people who they turn to for help, "Family members" was selected by more than half (56%). About a third of people turn to physicians (34%), and just over a quarter turn to friends as a resource to get help (28%). Only one in 25 mention using disease-specific associations to get the resources and help they need. This could be attributed to caregivers reaching out to individuals already in their circle before looking for other groups in which to connect about resources (Figure 19).

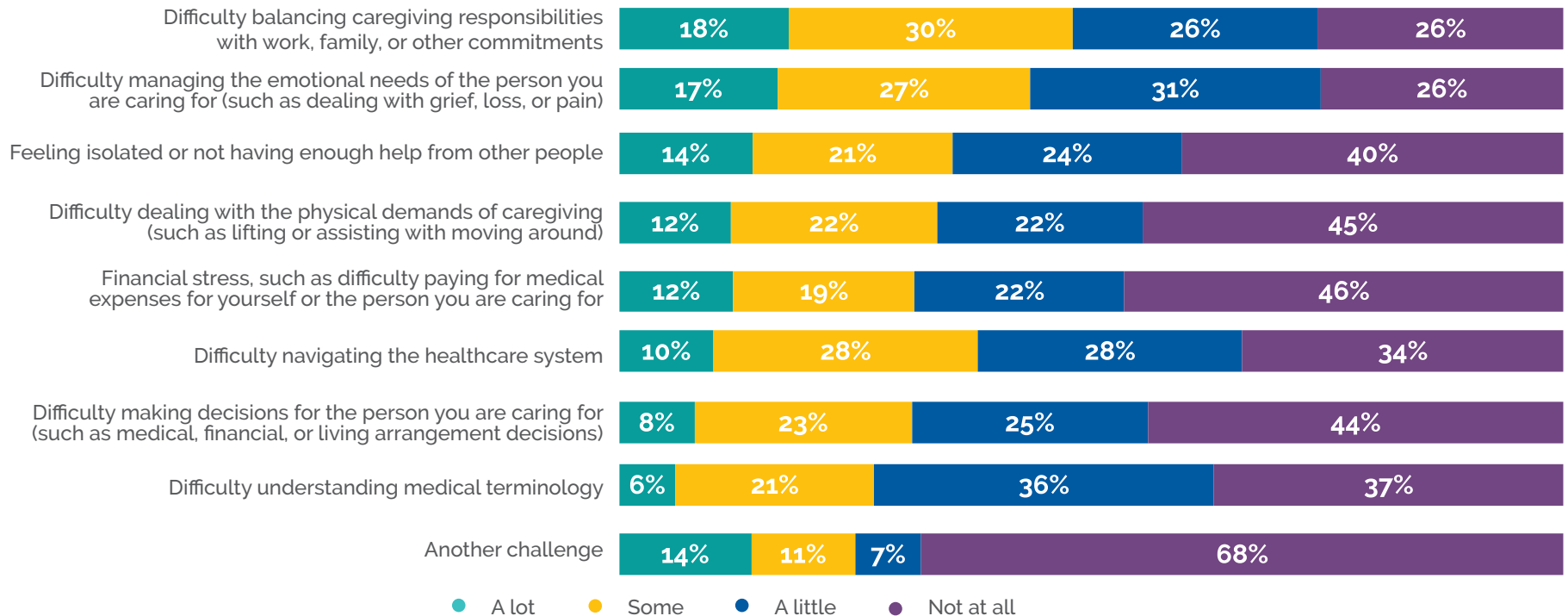
Figure 19. Have you used any of the following resources to get help in your role as a caregiver?



## Caregivers are most challenged by balancing caregiving responsibilities and their own personal commitments.

The two biggest challenges that caregivers experience most frequently are difficulty balancing caregiving responsibilities with other commitments (with almost 50% responding “Some” or “A lot”) and difficulty managing the emotional needs of the person they are caring for (with 44% responding “Some” or “A lot”). This, again, underlines the significant commitment and burden that caregiving can place on people. The next set of challenges, each affecting about a third of respondents, highlights feelings of isolation, the physical demands of caregiving, and financial stress. The two experiences that were the least chosen by respondents are difficulty understanding medical terminology and difficulty making decisions for the person they are caring for, which could be attributed to caregivers learning how to tackle these challenges consistently throughout their caregiving experience and not experiencing them as a daily challenging task. The profound impact of caregiving is evident here, as it connects the emotional, physical, and psychological burdens caregivers endure (Figure 20).

**Figure 20. How much do you experience the following challenges as a caregiver?**



Ultimately, this segment of PX Pulse highlights the significant burden shouldered by caregivers—roughly one in five people in the U.S. who self-identify as such. Emotional strain, logistical challenges, and systemic barriers all affect their ability to support their loved ones. This underscores a crucial opportunity to rethink how we provide better care and support for caregivers themselves.

# KEY TAKEAWAYS: A CALL TO SHARED ACTION

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At the start of this report, we highlighted how it represents a cross-section of consumer experiences within the healthcare system. Beyond data, it has uncovered insights that should drive meaningful action. Below are some of the key takeaways to consider:

- Consumer perception of quality remains steady but is still at its lowest point in our inquiries.
- Consumer perception of overall care experience ticks up slightly while suggesting an opportunity for improvement.
- While cost continues to be important to the U.S. consumer, so is quality.
- Importance of a good experience climbs slightly, while people continue to reinforce that their health and well-being are important.

As we looked at Star Ratings, we discovered a significant opportunity for a measure that impacts not only on how healthcare organizations are perceived, but also how they may be reimbursed:

- 69% of people had not heard of the Overall Hospital Quality Star Rating System
- 41% reported they have never used it

How can we help better inform people on how they make their healthcare decisions?

As we looked at control and engagement in healthcare experiences, people shared:

- The majority believe control should be shared between the patient and their care team.
- Most felt communicated to in ways they could understand and were addressed honestly in their care encounters.

These are consistently among the top priorities for healthcare consumers. So, in practice, it seems healthcare organizations are doing the things that matter most to people. Perhaps this explains why patient experience scores tend to be higher than perceptions of quality today.

The inquiry into caregiving revealed a great deal, with almost 20% of the U.S. healthcare consumer population reporting taking on a caregiver role in some capacity. They specifically shared:

- Most people who are caregivers are unpaid, and the majority provide long-term care for a family member.

- Most people have some difficulty navigating the healthcare system for the person they care for.
- The primary task caregivers take on is providing emotional support, followed by coordinating care.
- At the same time, they identify navigating health insurance issues as the most difficult task, followed closely by coordinating care.
- Caregivers are most challenged by balancing caregiving responsibilities and their own personal commitments, such as work and family.
- Ultimately, caregivers turn to other family members for help more than any other resource.

In looking at the cross-section of what we discovered in this release of PX Pulse, we get a true sense of the weight people carry as they experience healthcare today. We see the opportunities we have in making their healthcare journey better, by helping people understand where positive experience and good care is happening; taking the moment to learn about how people individually want to be engaged in their own care experiences; and seeking to support those (1 in 5 of us) who find themselves caring for someone else, most often a loved one, and understanding the ripple effects this has on families and communities.

In totality, the findings here challenge us that we can and must continue to strive to build, as The Declaration for Human Experience<sup>2</sup> calls for “a more human-centered, equitable, and effective healthcare system.” When we ask tough questions, when we seek purposeful insights, when we reflect on what we learn, and when we commit to action, that is when we can transform healthcare. While PX Pulse can be read as data on a page, we hope you see it as kindling for a more purposeful fire. It is clear the U.S. population is wanting and needing more from healthcare. It is up to all of us to ensure it happens.

# References

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1. Wolf JA. Consumer Perspectives on Patient Experience 2024. The Beryl Institute. 2024. <https://theberylinstitute.org/product/2024-global-healthcare-consumer-report-safe-care-communication-and-respect-lead-key-insights/>
2. A Declaration for Human Experience. The Beryl Institute. <https://transformhx.org/>

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