



Hiding in plain sight

Uncovering mental models to help solve the T2D crisis

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Introduction

Type 2 diabetes (T2D) is one of the greatest public health challenges of the 21st century. And despite available therapies, prevention programs, continuous glucose monitoring, digital tools and nutrition and exercise programs, we have failed to keep the disease in check. There are over 500 million people with diabetes worldwide—with the highest growth in disease prevalence in lower- and middle-income countries—and half of these people lack a formal diagnosis. There are over 33 million people with T2D in the U.S. alone, at a cost of over \$300 billion to manage their care. Further compounding the crisis, there are now 60 drugs available to treat T2D in the U.S. and an ecosystem of management options available. Yet, the share of people with T2D who are considered “well managed,” which is defined as having an HbA1c of 7% or below, is declining. The inverse relationship between the availability of T2D interventions and the trend in disease outcomes is a hallmark of our national public health crisis.

Behind the metrics are individual people who spend each day trying—and often struggling—to manage their diabetes. Given the evident limitations of treating T2D with pharmacology alone, the healthcare industry is exploring interventions that instead drive behavior change, particularly those that ease engagement with T2D management. This attention has resulted in new devices, such as continuous glucose monitors, and in new digital tools to help with diet, exercise and medication adherence. Patients’ continued lack of success suggests the need for an alternative approach to managing care. Most patient research focuses on self-reported choices or observed behaviors, often overlooking the key insights that can emerge from examining how patients make decisions.

Understanding patient decision-making through mental models

To better understand the decision-making processes of patients with T2D, ZS explored the beliefs and “mental models” that shape health behavior. Mental models are individual representations or characterizations of everyday phenomena, including how we perceive ourselves and others around us. Examples of mental models include the age at which we perceive someone as elderly or our comfort with making decisions about our own health without consulting a doctor—measures that vary among people.^{1,2} Advances in cognitive psychology delve into understanding these “internal knowledge structures” and their impact on our expectations and judgments. These mental representations both inform and shape our choices.

Through our research, we sought to determine which mental models are common among patients with T2D. Our initial review of published studies suggested that T2D patients' fatalism, learned helplessness and deference to authority strongly influence how well those patients are able to manage their self-care. Fatalism, or a sense of futility, is the product of mental models regarding the individual capacity to affect future outcomes. Fatalists' mental models generally reveal a lack of agency and a sense that processes are beyond their control. Luckily, patients with T2D are not broadly fatalistic. Only 18% of the patients surveyed feel that their actions cannot change their futures. Our patient research set out to explore:

1. The mental models that dominate in patients with T2D and lead to good diabetes management behaviors
2. Changes in patient behavior when patients use these mental models effectively
3. Whether healthcare stakeholders ought to focus attention not only on patient behaviors but also on the mental models that lead to or influence those behaviors

Throughout this white paper, we refer to diabetes management interchangeably with self-care. For our purposes, diabetes management or self-care refers to diet, exercise, medication adherence and blood sugar monitoring, often as recommended or prescribed by healthcare professionals. Additionally, we make a distinction between subjective perception and objective behavior. Rather than ask survey participants about how frequently members of their household participated in their diet, for example, we asked for their perception of their household's participation. Likewise, we asked patients for their perception of the distance to a gym or a grocery store, rather than measure the mileage objectively. We call these perceptual maps collectively the "dynamic lived environment" mental model, which captures patient's "internal knowledge structure" of the features of their physical environment. As a result, our data captured critical, independent variables in decision-making processes. That is, the frameworks patients employ to navigate their world based on the mental maps they have formed.

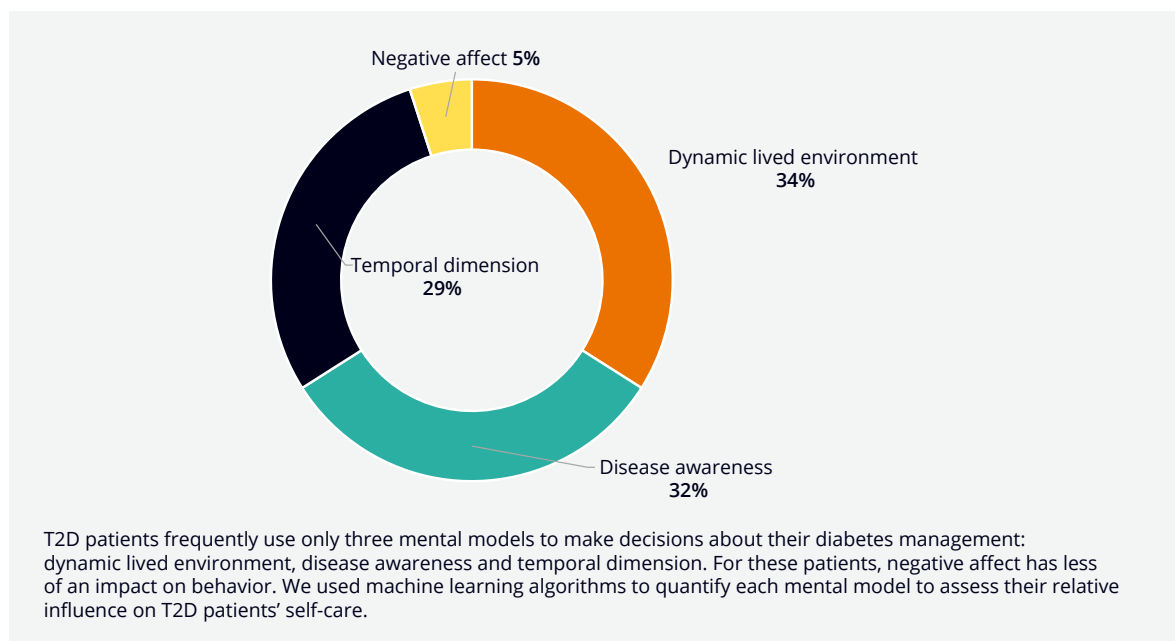
For a more detailed explanation of our research, please see the Methodology section on page 12.

Mental models for behavior change in T2D management

Based on our reading of the existing literature, we expected many different cognitive factors to influence self-care. But in our qualitative interviews, we found three major mental models predominately influence patient decision-making: dynamic lived environment, disease awareness and temporal dimension. Figure 1 quantifies the relative effects of each variable uncovered in our research.

FIGURE 1:

The mental models T2D patients use most frequently to make decisions



Our analysis used machine learning algorithms to connect psychological variables and mental models to behavior supported by our qualitative finding that better diabetes management is equally driven by these three mental models (Figure 1). We concluded that interventions aimed at improving patients' diabetes management should therefore focus on temporal dimension, disease awareness and dynamic lived environment.

Our analysis also indicates that, contrary to expectations, diabetes management could only be slightly improved by focusing on patients' negative affect. Negative affect is the psychological term describing patient dissatisfaction with the current state of their affairs, such as when they fail to achieve a goal or to avoid a threat. Patients often respond with inaction or hasty decision-making when their emotions are heightened.

We believe our finding that negative affect plays only a small role in patient behavior can be linked to the discovery that only 38% of patients report speaking with their doctor about stressors and how stressors impact their health. Patients with an annual household income of under \$40,000 are even less likely to discuss stressors with their doctors, as only 19% report doing so. In our qualitative interviews, patients with T2D said that while they talked about the burdens they feel while managing their disease, they largely aren't voicing those concerns to their healthcare professionals (HCPs). That lack of vocalization may create a dissociation in the patient's mind between negative affect and management behavior, for which our research is unable to solve. Future research would need to probe further into this dissociation and its causes.

Potentially more alarming is that 22% of patients who had spoken to their HCP about stress, a form of negative affect, said their HCP suggested that stress does not matter to diabetes management. That share rises to 43% of Hispanic patients reporting stress to their HCPs. This highlights the disparities in care that different demographic groups face when managing diabetes. That stress is inconsequential to diabetes management is demonstrably false, and that any patient understands otherwise from their doctor is alarming. While only a minority of our respondents (8%) report hearing that claim from their HCP, because of the prevalence of T2D in the U.S., that small sample represents millions of patients.

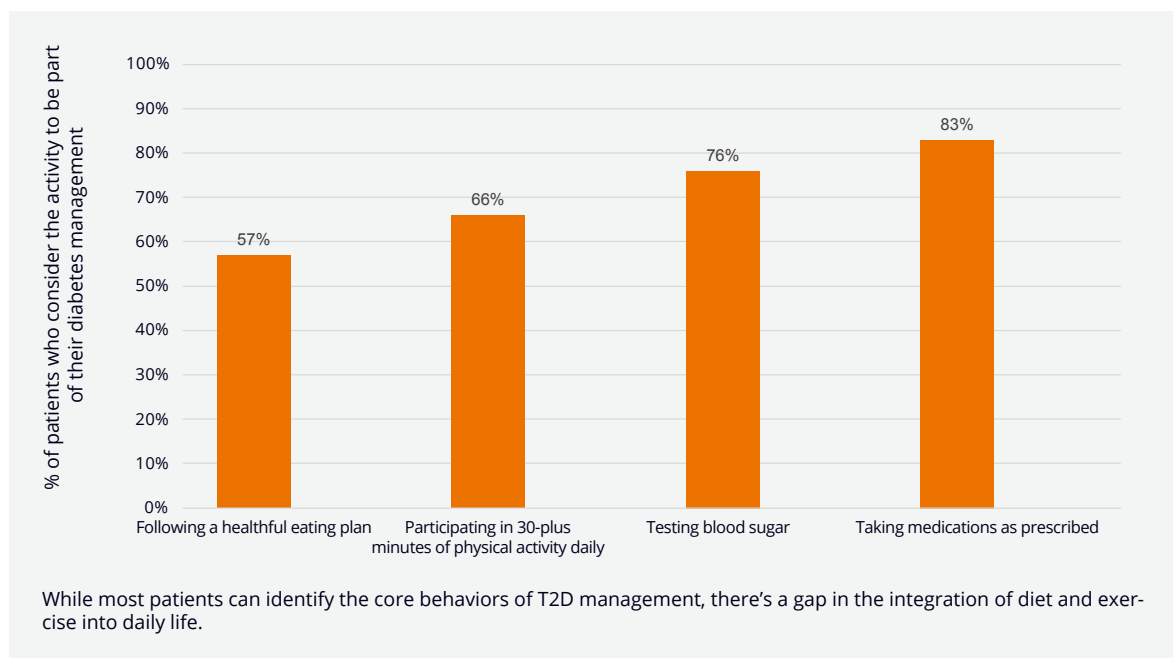
Developing disease awareness and better management behaviors

Despite the existence of several educational tools for diabetes management, we still find that patients have a narrow view of diabetes management and an inaccurate understanding of optimal behavioral responses to a diagnosis. As one patient told us, “Since finding out I have T2D in 2015, it really scared me in the beginning. I didn’t know what to eat and how to manage it. Now, seven years later, I’m not as scared but I know I need to take it more seriously.”

Figure 2 shows that only a slight majority believe that healthful eating figures into diabetes management. More alarming, 17% of patients do not believe that taking medication as prescribed is part of diabetes management, and almost one in four report a similar attitude toward testing their blood sugar. Much of this awareness gap is driven initially by anxiety or patients not taking the diagnosis seriously.

FIGURE 2:

Activities that patients consider to be part of their diabetes management



Patients who recognize the four core facets of diabetes management do better at their own self-care. We see the greatest effects among patients who recognize the impact of participating in physical activity or testing their blood sugar. Patients who recognize that physical activity is part of diabetes management are 45% more likely to participate in the recommended level of daily physical activity. This link between knowledge and behavior may be unsurprising, but it underscores the importance of establishing proper diabetes awareness, or targeting mental models, throughout a patient's journey.

Disease awareness differs most by ethnicity rather than by income. This distinction is important. Our survey found that Asian-American patients are most likely to recognize physical activity, healthy eating and monitoring blood sugar to be part of diabetes management, while white patients, more so than any other group, recognize that taking medication as prescribed is part of diabetes management. Native American and Native Hawaiian patients are less likely to recognize the four core facets of diabetes management, reflecting the need for education that is culturally informed.

Small, actionable ways to build confidence

The majority of patients surveyed report being satisfied with their current health (58%), though this share drops precipitously as annual household income decreases. Only a third of patients with an annual household income under \$40,000 rate themselves as satisfied with their present health. And this pattern across the income distribution continues in other areas. Overall, nearly 80% of patients report that they are motivated to change their current health, but this share drops by roughly 10% for those reporting lower annual household income.

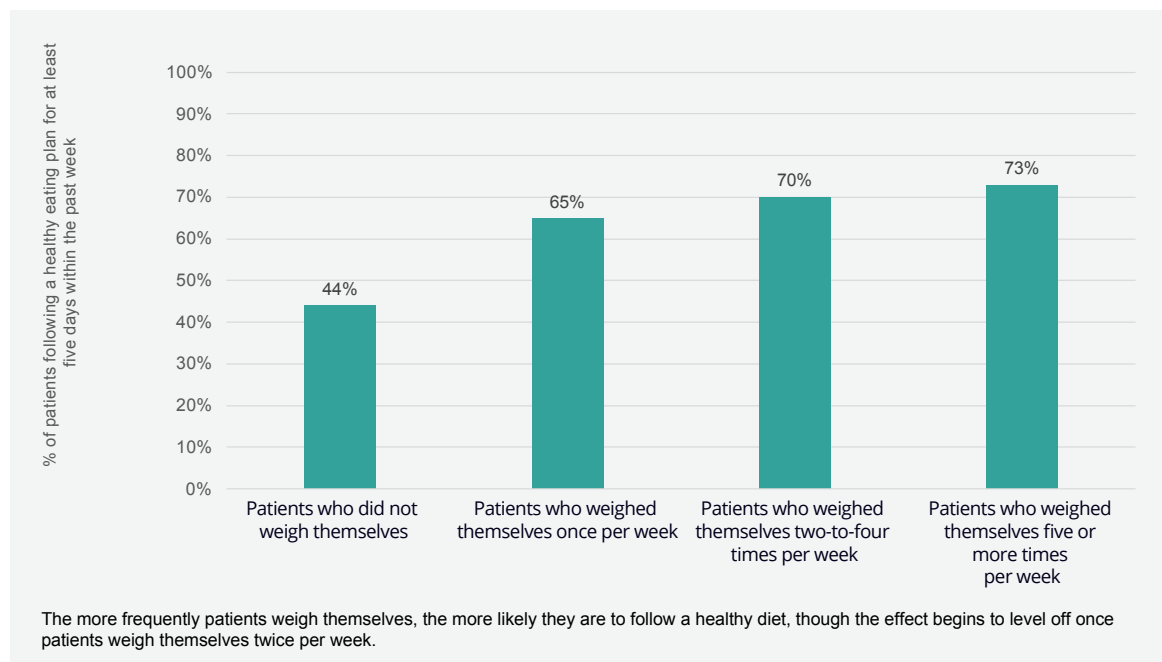
“I want to try and control it by diet and exercise so I don’t have to take metformin anymore! Maybe I can get rid of it completely.”

The good news is that the motivation to prioritize diabetes management does not vary by ethnicity. And even at lower income levels, most patients believe that they can change for the better. This finding and others like it suggest that mental models govern differences in patients’ present and future health behavior. That is, patients have distinct modes of weighing the present against how the future affects their decisions. We call these differences the “temporal dimension.”

One simple method for improving the odds of succeeding at a long-term task, such as weight loss, is to set discrete, measurable goals, such as losing half a pound per week. We find that patients who weigh themselves at least once a week are 20% more likely to follow a healthy eating plan (Figure 3), and that number continues to increase slightly for patients who weigh themselves even more frequently. HCPs can easily communicate these sorts of stepwise goals to their diabetes patients, and household members can easily participate to improve patient adherence.

FIGURE 3:

Relationship between patients who weigh themselves and healthy eating habits



Asked how long they would take to enact changes, such as weighing themselves weekly, patients say they believe they can enact meaningful change within three months. For some aspects of diabetes management, such as monitoring blood sugar daily or taking medication as prescribed, these changes may require less planning to accomplish. Changes such as following a healthful eating plan or participating in at least 30 minutes of daily physical activity, however, are likely to take more effort to sustain. Where consistency and sustainability are critical for meaningful impact to occur, behavioral changes require a longer-term vision. Patients need to communicate these goals and develop actionable plans to achieve them, while incorporating broad accountability into their goal planning.

Patients need emotional and physical support to succeed

Mental models of the dynamic lived environment capture how patients internalize physical and environmental factors when managing their diabetes. During qualitative interviews, we heard that patients receive “emotional support” managing their diabetes, and that observation was corroborated during quantitative surveying. Fifty-seven percent of patients report receiving adequate emotional support, though that share declines along with income: 73% of patients with an annual household income of more than \$100,000 felt that way, compared to just 42% of patients with an annual household income under \$40,000.

“Often, I have to cook other meals because not everyone in my house is diabetic, so that is a struggle. I struggle with finding the time to exercise. I also struggle with taking my medication as prescribed. I forget a lot of time, especially when I’m in a hurry.”

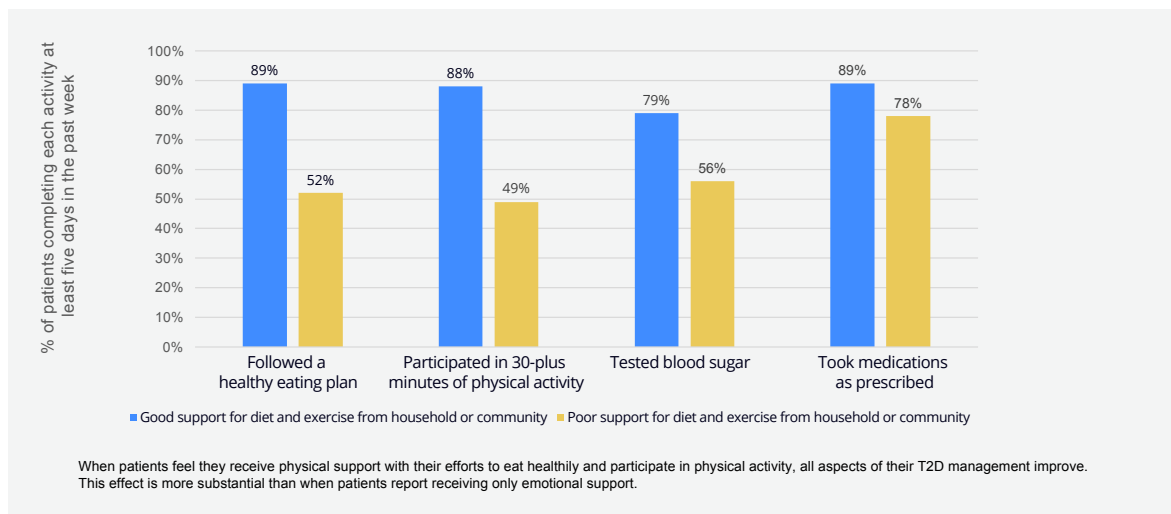
But household members can provide support that extends beyond emotional cooperation. By mirroring diabetics’ diet and exercise regimens, household members provide “environmental support” that produces even greater health results. This environmental support is critically lacking for most patients. Only 18% of patients with T2D report that their

household follows their diet and physical activity requirements. And the figures become more concerning as the questions become more atomized. Patients reporting that their household follows their diet but not their activity requirements (17%) outnumber those who report that their household follows only their physical activity requirements (5%). Once again, the data also changes by ethnicity. White patients, for instance, report the biggest gap (29%) between their household members following their prescribed diet and household members following their physical activity requirements.

The figures are particularly salient because our data indicates that emotional support alone is insufficient to initiate behavioral changes in patients with diabetes. Those with adequate emotional support report slightly better diabetes management, but the difference is not statistically significant. Environmental support, in contrast and as shown in Figure 4, changes how patients manage their diabetes across all behavioral factors studied. When household members follow along with both diet and exercise requirements—the core facets in which they can directly participate—patients with T2D report adhering better to all core aspects of their management plans. The data points to the importance of household or community interventions in improving personal health, and, as a result, population health.

FIGURE 4:

Rates of household support for diabetes management activities



Implications for providers, payers and life sciences

The management decisions that patients with T2D must make every day, from their diets to their physical activities to their medications, can often amount to a taxing mental and physical burden, and patients may use shortcuts to reduce this burden. Providers that oversee care for patients with T2D have in the past omitted or discounted the more distributed structural and social processes at work, focusing almost solely on providing patients with pharmacological solutions while ignoring their environments, their experiences and the mental models that shape serial decisions. In reality, physical and mental environments are intimately associated with patients' approaches to diabetes management and are integral influences on behavior.

Our study demonstrates that key mental models—defined as structured knowledge that informs choice—play a greater role in determining diabetics' health behavior patterns than previously acknowledged. While these sorts of psychological factors are well documented in academic research, including in the health decision science field, they are not yet systematically accounted for in client-driven customer research. By understanding mental models and other group differences, for example between ethnicities and socioeconomic statuses, HCPs can become better informed about unmet needs and potential opportunities, resulting in more holistic, humane and sophisticated patient care. Testing attitudes and measuring behaviors is insufficient. Stakeholders across healthcare must invest more in research that operationalizes best practices. We need more research that looks more deeply into the minds of patients and asks what really motivates their decisions.

By combining qualitative interviews—informed by a synthesis of health-decision literature—with a quantitative survey testing mental models, attitudes and self-reported behaviors, we form a more complete picture of patients with T2D. This research can inform the interventions that payers and providers design to improve patients' diabetes management. For instance, the study suggests that early interventions that help bring household members into the patient's journey with clearly defined, discrete goals will yield substantially positive effects. Likewise, basic patient education remains essential, but education targeting the household or community will realize a bigger impact on behavior.

But for life sciences to act on this research, they must continue to recognize that the relationship between patients and their HCPs remains essential. In our survey, patients ranked themselves as the most important agents in managing their disease, with healthcare professionals a close second—65% of study patients reported deferring treatment decisions to their diabetes care team. A majority, for instance, will decline a continuous glucose monitor if their HCP advises against one, even if a friend recommends it and the patient has done their own research. While HCPs ought to work hard not to lose this powerful trust, life sciences can advocate for more appropriate interventions at the right times, for example by updating HCPs with the latest diabetes management innovations. Doing so in the context of setting near-term, actionable goals within a longer-term roadmap, and engaging with the patient's culture and household, are likely to deliver better results.



Methodology

Our work began with a subject matter expert report that synthesized some of the available literature on diabetes decision-making and risk analysis. We used scientific publications to populate a list of 10 psychological factors and mental models to test with patients in qualitative research.

We conducted 25 in-depth qualitative interviews in July and August of 2022 via Zoom, adapting ethnographic approaches to have patients describe their mental models and identify resulting behaviors. Based on these interviews, we narrowed the list of psychological factors to the five mental models most influential on patients with T2D, as documented in the table below.

FIGURE 5:

The 5 most important mental models influencing diabetes management tested in this research

Mental model	Description
Temporal dimension Distributed choice, inter-temporal choice	Future discounting, present bias (adhering to management plan now versus later, expanding effort now versus serious complications/hospitalization later)
Dynamic lived environment	Mental map and impact of lived environment, physical and social, on patients' attitudes and decision-making in the disease management process
Negative affect	Depletion of mental energy, hasty decisions, immediacy and a fallback to habit or convenience Feed forward mechanism of negative affect to judgement and behavior
Diabetes awareness	Awareness and recognition of key activities, such as healthy diet, exercise, blood sugar monitoring and medication adherence, as part of diabetes management
Social roles/deference to authority	Patients take a subordinate role in their relationships with HCPs; defer decision-making power to others

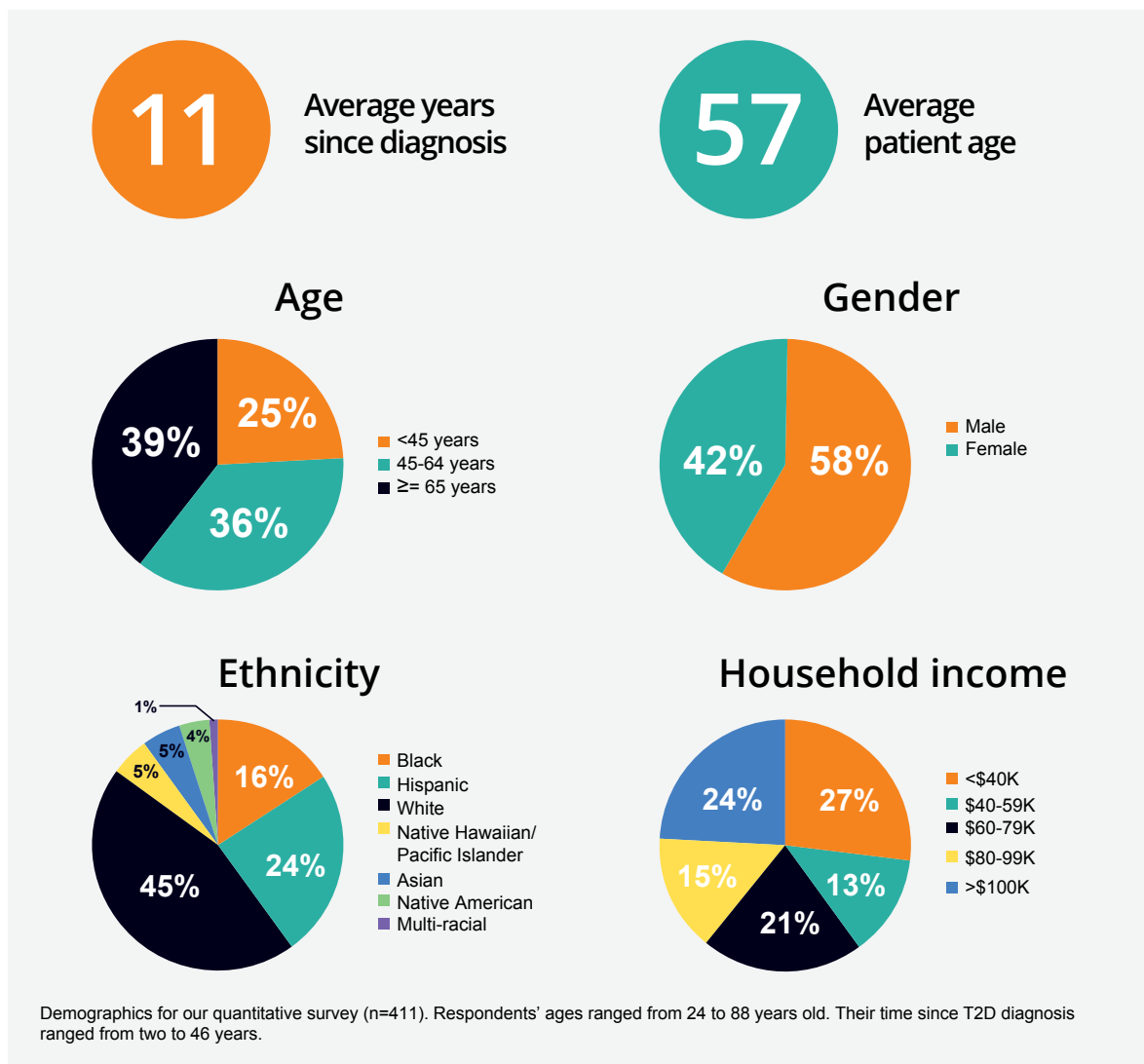
Our quantitative research to measure the above models against each other began by surveying 411 U.S.-based adults with T2D in September 2022 using an online survey. Our sample was screened to match current U.S. demographics across ethnic and income groups (see Figure 6). Respondents self-reported their ethnicity, household income, age, years since diagnosis, gender, percentage of time with different HbA1c levels and location within the U.S. All respondents were over 18 years old, had T2D for at least two years and had their diagnosis confirmed by an HCP.

Included in this quantitative survey were two validated scales to measure self-reported diabetes management: the [Summary of Diabetes Self-Care Activities \(SDSCA\)](#), which

asks survey respondents how well they have adhered to different aspects of diabetes management in a seven-day period, and the Risk Perception Survey-Diabetes Mellitus (RPS-DM) to understand how patients assess future risk that may be caused by their diabetes. Findings were tested for statistical significance using Student’s t-test at a confidence interval of 95%. We indicated statistical significance where appropriate.

FIGURE 6:

Demographics for ZS quantitative survey respondents

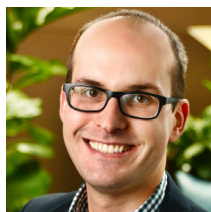


Finally, we utilized XGBoost to quantify mental-model drivers of stated patient behavior—that is, how different mental models improved or limited a patient’s ability to manage their diabetes successfully. Given our limited sample size, we pooled respondents for this analysis. Our model produced an R^2 of 0.35 and a training R^2 of 0.56, indicating only weak-to-moderate fit—nevertheless a reasonable result considering the number of factors influencing behavior that our online survey could not account for. In context of our other results, we believe a larger sample size would return similar findings, while making the model more accurate.

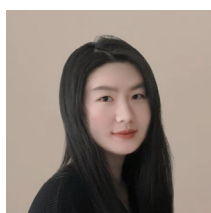
References

1. Bradford W. Hesse, “Decision architectures” in “Handbook of health decision science,” ed. Michael A. Diefenbach, Suzanne Miller-Halegoua and Deborah J. Bowen (New York: Springer, 2016) 15-27.
2. P. N. Johnson-Laird, “Comprehension as the construction of mental models,” *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*. Volume 295, No. 1077 (1981): 353-374.

About the authors



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