Worthy

Personalizing health care through shared decision-making

PART FIVE

What does Harry Potter have to do with improving health care?

I sometimes ask people inside our company to do what I call the "magic wand" exercise.

The idea is pretty simple: Pretend you have an all-powerful magic wand that can overcome any obstacles. How would you use it to solve the business problem or opportunity that you are facing? Much like in the Harry Potter books and movies, the wand's power is not limited to one spell. It can be used as many times as needed. In fact, I also ask my Worthy Podcast guests how they would use a "magic wand" to change health care in America, and you can listen for a compilation of their responses here.

The point of this exercise is to free the human mind to dream big, focus on what is possible, and imagine a much better future. Too often, we cut or edit some of our best ideas because we identify all the potential problems and obstacles and worry prematurely that those ideas just aren't feasible. The end result is that even when you ask people to think and dream big, they may come back with very incremental responses.

But when given an all-powerful magic wand, it forces people to let go of those worries and challenges and free their imagination. Naturally, to get anything done, we eventually have to return to all those pesky obstacles, but hopefully we'll be starting with a much more compelling future vision, which should make tackling those issues worthwhile.

All this is background for this month's Worthy segment because it is entirely dedicated to using the metaphorical magic wand to create care that is Worthy of us all. Put another way, what you are about to read is how I would want my loved ones to be treated by the American healthcare system if I had the power to make it happen. I will also address how to do this, including how to deal with the potential challenges of implementing these changes.

While it will probably be less exciting for some of you than a Harry Potter movie, the good news is that I won't have to duel with Lord Voldemort. At least, I hope not!

READ MORE

Creating the framework →

The end of prior authorization? →

How to make shared decision-making a reality →

Some examples →

What is next? →

Most importantly, hang on to that magic wand! →

PART FIVE

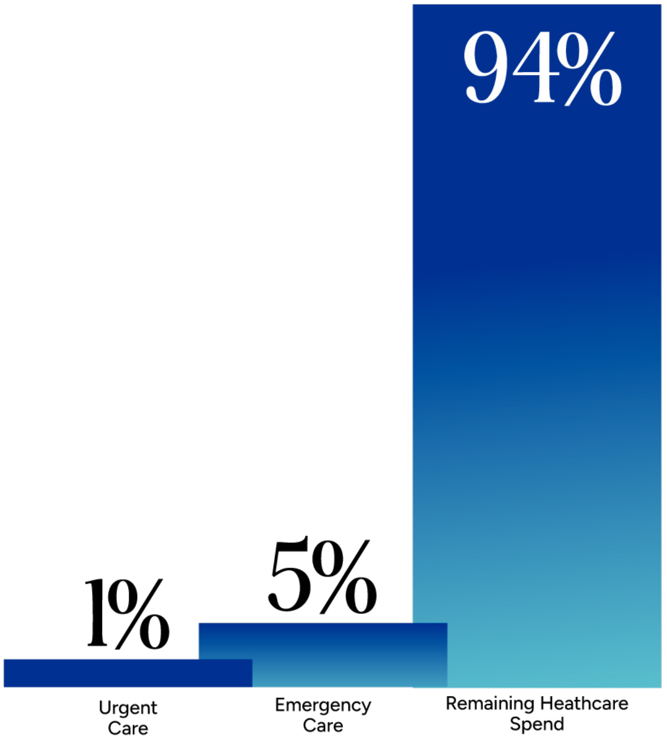
Creating the framework

First, I am making the assumption that the patient can afford the health insurance premiums and out-of-pocket costs associated with their care in all of the scenarios summarized below. This is not true for everyone today and it needs to be addressed. However, in order to focus exclusively in this segment on how to deliver care Worthy of us all, I am making this important assumption. We'll talk about how to ensure everyone can afford care in future segments.

The second assumption that I'm making is that we are not focusing on emergency and urgent care. If someone is experiencing the symptoms of a heart attack or they broke a limb, they should immediately seek treatment from an appropriate professional. We should set and monitor the quality of emergency and urgent care and constantly look to improve them, but often in these situations what matters is both how quickly and how effectively care is provided – as viewers of the series, "The Pitt" know all too well.

That said, a significant share of health care, including for emergency department (ED) visits, is for potentially non-urgent reasons, as shown in the below chart (NCQA). I believe that the vast majority of non-emergent, non-urgent care, including treating acute conditions (e.g., cancer, maternity, surgeries) and chronic conditions (e.g., diabetes, hypertension, chronic heart failure) can and should be done through a personalized, shared decision-making model. That is the focus of this segment.

Healthcare that is non-urgent, %[1]



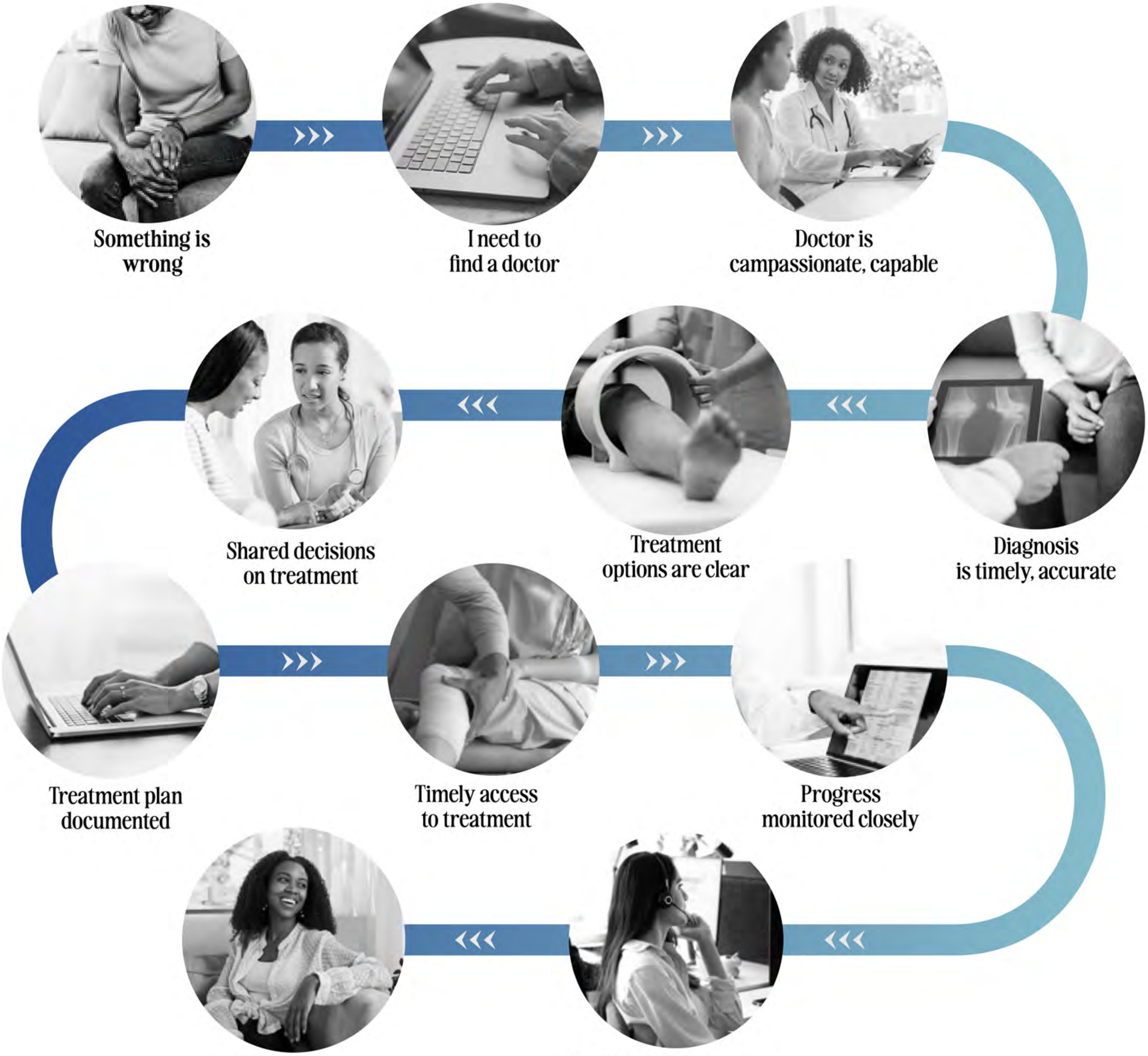
[1] Estimate assembled from CMS National health spending totals, peer-reviewed research on ED spending, AHRQED cost data, and current urgent care market estimates

Given these assumptions, the question becomes, what is care that is Worthy of us all? For me such care includes:

- Thorough, accurate, timely, and relevant information that you can easily access, understand, and use to choose (a) healthcare provider(s)
- Timely access to healthcare provider(s) who:
  - Are highly capable/competent in the care you need
  - Know everything about your healthcare background and condition(s)
  - Understand your interests and preferences
  - Have your best interests (and nothing else) in mind when making recommendations and decisions
  - Are willing and able to communicate clearly and effectively with you and your loved ones when appropriate
  - Provide timely, thorough, high-quality service
- Timely, accurate diagnosis, based on all of your relevant historical medical information, including visits with other clinicians, that is clearly explained
- Clear, comprehensive distillation of treatment options and the potential benefits and risks of each, based on the latest credible evidence, facts, and research
- An in-depth discussion between the healthcare provider(s), you, and your loved ones to make a shared decision about the best course of treatment (including the opportunity for a second opinion should that be preferred)
- A clear treatment plan and schedule so everyone knows what to expect to happen when, and how results will be monitored and communicated
- Timely access to and effective performance of all elements of the treatment plan
- Close monitoring by healthcare providers and/or team as to how the treatment is going, and what, if any, changes need to be made, in a timely fashion
- A consistently high level of service from all involved, including no administrative hassles or distractions to add stress or confusion to an already stressful situation
- If applicable, a “closing discussion” after recovery is complete, with clear, written guidance as to how to stay healthy including a review of the type and duration of potential side effects associated with treatment

See the next page for a visual representation of what care Worthy of us all looks and feels like to me.

Health care that's Worthy of us all



Something is wrong

I need to find a doctor

Doctor is campassionate, capable

Diagnosis is timely, accurate

Treatment options are clear

Shared decisions on treatment

Treatment plan documented

Timely access to treatment

Progress monitored closely

High level of service – no administrative hassles

Close out conversation

The "shared decision-making" approach to selecting a treatment option was first introduced as an idea by Dr. Jack Wennberg and his colleagues at the Dartmouth Institute over 30 years ago. He and his colleagues did a lot of impressive research over many years identifying regional variations in physician practice patterns and developing patient guides on preference sensitive care that helped reduce these variations and improve outcomes (see some samples of their work in these links: Wennberg,1973; PubMed).

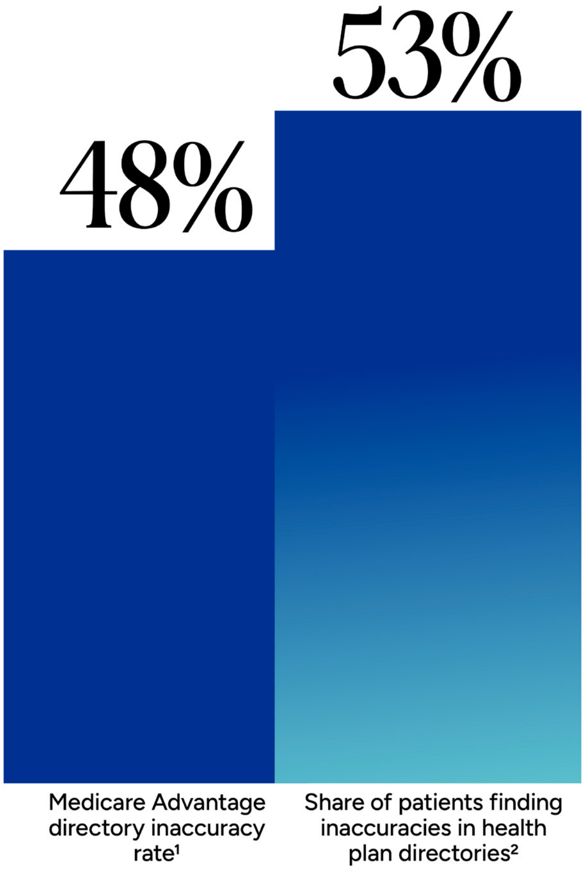
A modern, broader, artificial intelligence-powered version of Wennberg's shared decision-making model is at the heart of the personalized approach presented here.

Hopefully, this vision resonates with you. The steps could vary a bit depending on an individual's personal history, but generally, this broad set of conditions and steps is what I look for when my loved ones need care. It feels logical to me that a patient should be able to choose the appropriate provider with confidence, expect that provider and their support team to perform at a high level, and experience a smooth, hassle-free process while receiving a diagnosis, determining, implementing, and monitoring a treatment plan and getting advice on how to remain healthy once they've recovered.

While we can probably all agree on the general approach, this is not how things work today, at least not consistently. Therefore, it is worth taking a moment to look at some quantitative and qualitative data on how our current healthcare system is doing relative to this aspiration.

Provider directories have high inaccuracy rates

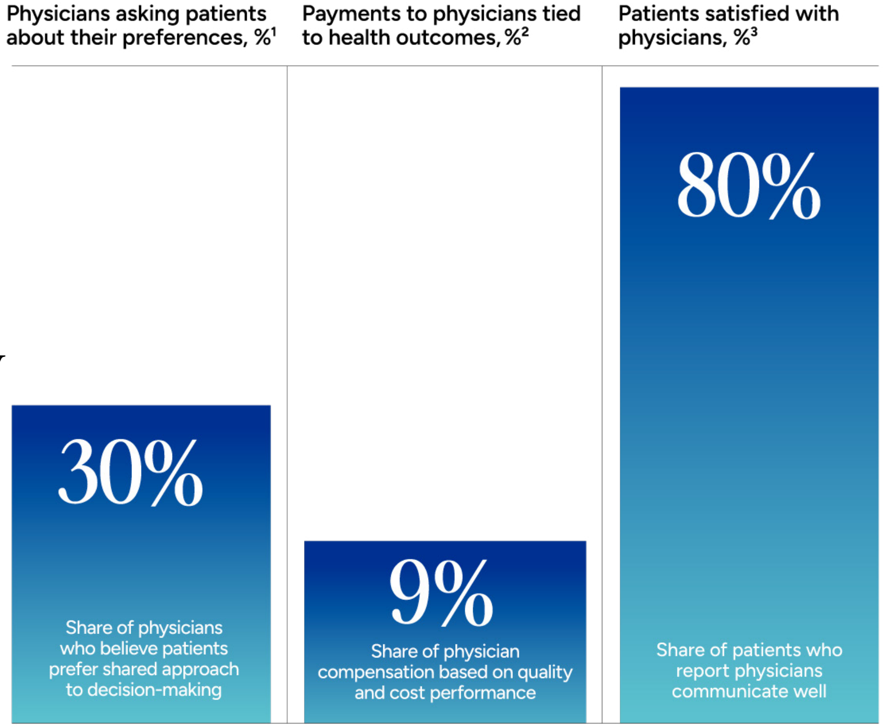
Inaccuracy of provider directories, %



[1] Based on 2018 CMS study on online provider directories for MA plans;

[2] Based on a 2020 Health Affairs study on "Incorrect Provider Directories Associated with Out-of-Network Mental Health Care and outpatient Surprise Bills"

Patients have high satisfaction with physicians' communications despite inconsistency in inquiring about preferences or being rewarded for outcomes



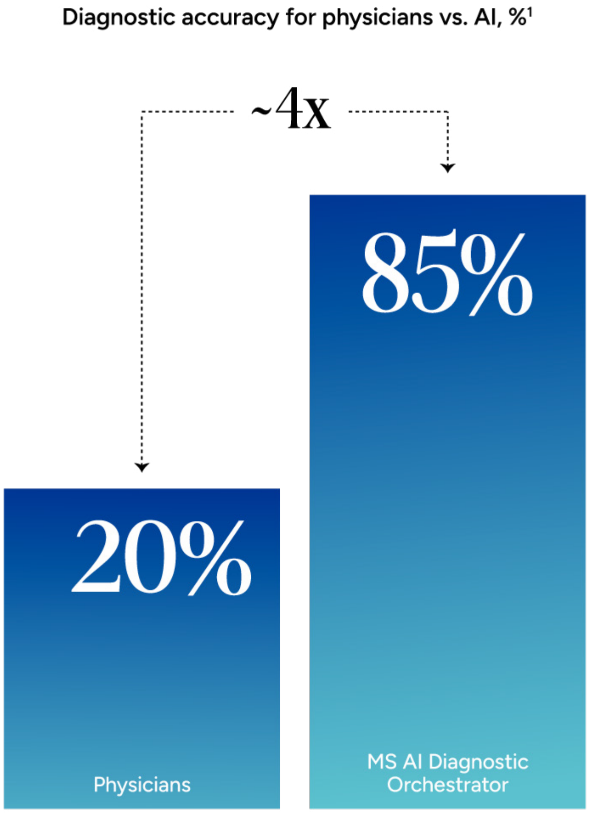
[1] Based on 2023 survey published in Translational Behavioral Medicine with respect to multiple myeloma cases

[2] Based on 2022 JAMA cross-sectional-mixed-methods study on physician compensation arrangements and financial performance incentives

[3] Based on 2024-2025 HCAPHS survey results

SOURCE: Translational Behavioral Medicine, JAMA, HCAPHS

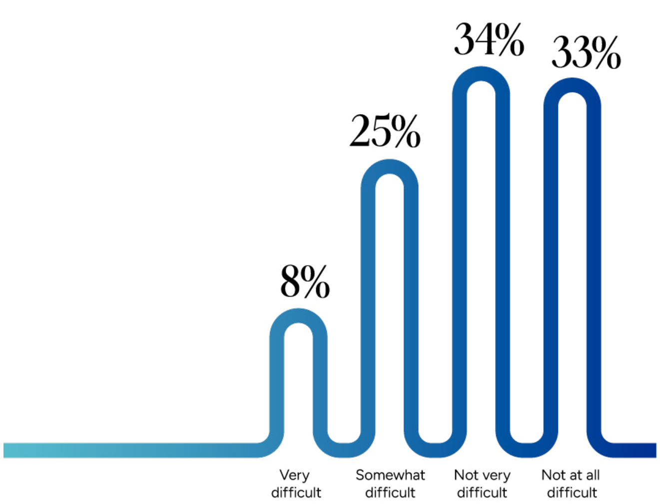
AI is already outperforming most physicians for diagnostic accuracy



[1] Based on 2025 study by Microsoft on the accuracy of the Microsoft AI Diagnostic Orchestrator (MAI-DxO) for cases in NEJM

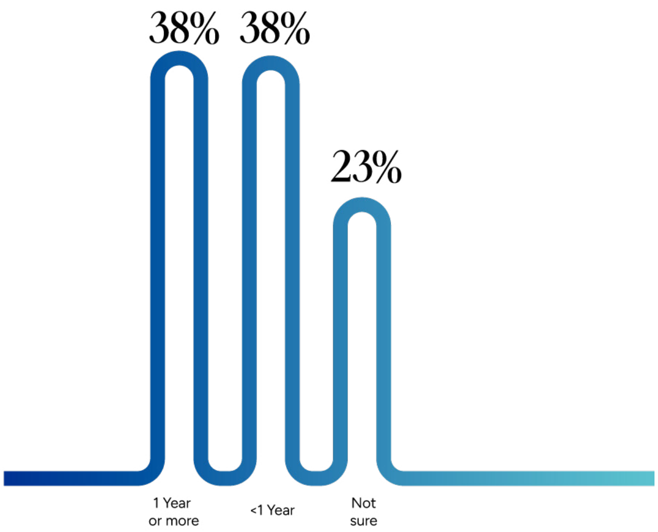
Not surprisingly, patients have an inconsistent experience when it comes to getting a timely and accurate diagnosis

Share of patients reporting difficulty receiving accurate diagnosis, %[1]



[1] Based on 2025 survey results of patient conducted by the PAN Foundation

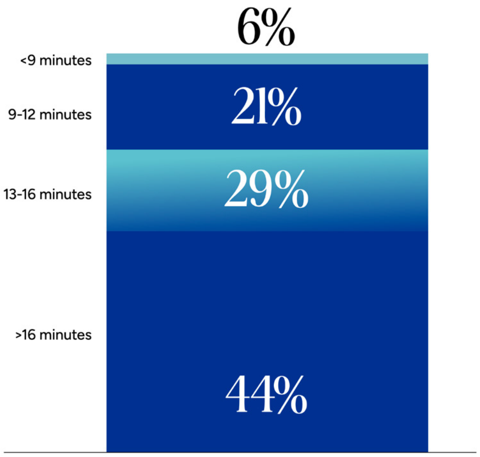
Time reported between initial onset of symptoms and diagnosis, %[1]



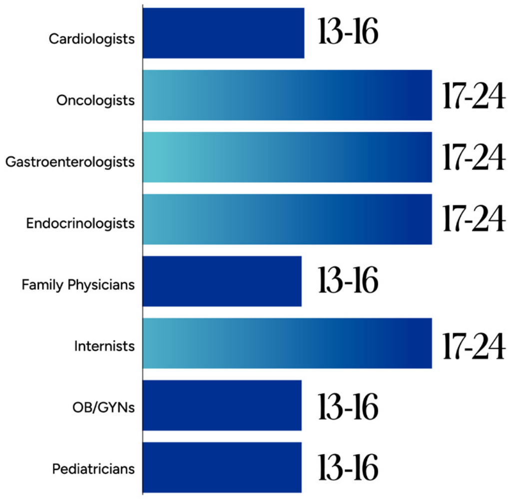
SOURCE: PAN Foundation

Patients can feel "rushed" in their typically limited time interacting with physicians, which can be a barrier to creating the feeling of a trusted partnership

Amount of time physicians spend with patients, % of physician survey respondents[1]

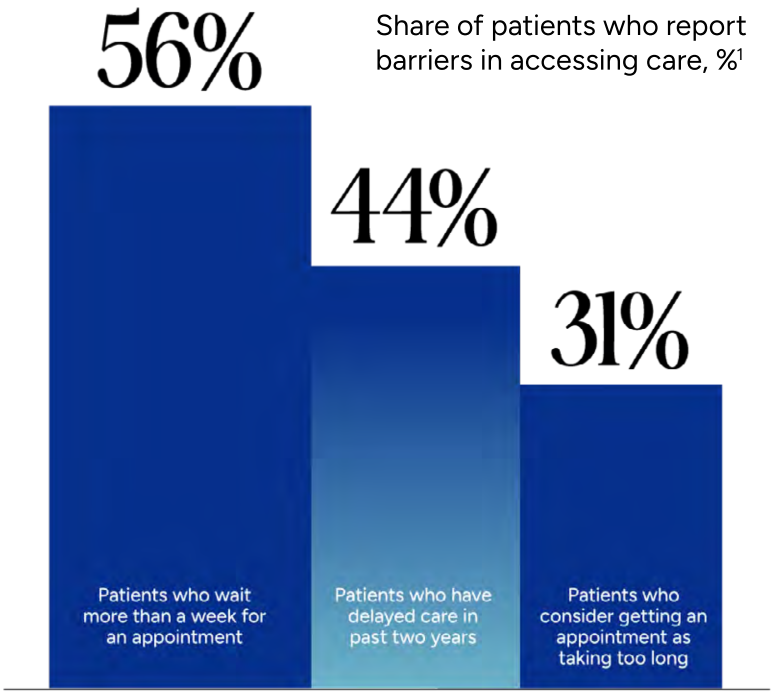


Most frequent range of time physicians spend with patients by specialty, minutes[1]



[1] Based on surveys conducted by Medscape on physicians from 2017 and 2018

Getting an appointment can be challenging



[1] Based on 2023 survey results of 2,500 adults as reported in the AAPA-Harris Poll

SOURCE: AAPA

Beyond the numbers, consumers have frequently shared frustration with various aspects of accessing and receiving care. While the table below is not an exhaustive list of concerns raised, it does represent some common complaints.

Care Worthy of us all	Common concerns/complaints expressed by consumers
Thorough, accurate data to choose a provider	Beyond accuracy issues with provider directories, consumers often complain about the lack of access to insightful/helpful information (e.g., quality scores, specialization of providers such as psychiatrists).
Timely access to capable providers who know you and have your best interests in mind	Challenges with scheduling a timely appointment, long waits in the waiting room, and feeling rushed through a short visit with a physician who makes more eye contact with a computer than with the patient are fairly common concerns. It is also far too common that physicians, hospitals, and/or other healthcare providers have incentives to provide certain types of treatment irrespective of whether it is best for the patient.

Timely, accurate diagnosis	Beyond the relatively low accuracy of initial diagnoses in general, an ultra-rare disorder is defined as an illness that affects fewer than 1 in 50,000 people. This makes it difficult to get a timely, accurate diagnosis. While these disorders are individually rare, collectively there are so many ultra-rare disorders they are pretty common (The Economist estimates about 300 million people or about 3.5% of the world's population suffer from one of them). In addition, individuals and their clinicians can struggle to determine that they are suffering from a behavioral health issue such as depression or anxiety.
Clear compilation of treatment options	Before consumer-accessible artificial intelligence arrived on the scene, websites and other tools were created to help patients learn more about their potential illness/condition, however, these tools were mostly general rather than specific to the patient. While there have long been care guidelines for physicians, they are usually not written in language that can be understood by the average American. Rapidly developing tools are being adopted to help physicians with diagnosis and treatment such as Open Evidence. However, there appears to be a significant gap when providing this kind of information to patients, as evidenced by a large and growing number of people feeding their specific healthcare information into large language models like Claude and ChatGPT in search of assistance.
Shared decision on treatment	While there are clearly individual physicians in certain specialties that make a habit out of this (for a wonderful example, please watch my podcast with Dr. Join Luh – a radiation oncologist who takes the time to get to know his patients and discuss treatment options), this is not the typical scenario for most patients.
A clear treatment plan and schedule	While it is common for physicians and their offices to have educational brochures that provide background information, based on consumer feedback, establishing a truly specific and personalized care plan and schedule is, at best, inconsistent.
Timely access to treatment	The wait time for getting access to appropriate specialists, and the sometimes long and challenging process of prior authorization by health plans, are probably the most common complaints on timely access to treatment.

Progress monitored closely	Monitoring can vary dramatically depending on patient circumstances and the individual physician and their team. For example, progress can be followed closely in acute situations such as cancer but not always followed closely with more chronic illnesses like diabetes. It is probably fair to say that this is highly inconsistent today.
Consistent, high level of service -- no administrative hassles	It is uncommon for patients to feel that accessing their care is hassle-free. Even if care is authorized by a health plan, the process of going through it can be time consuming and stressful, as can the many confusing bills and documents associated with healthcare claims. Long wait times before and between visits and tests, as well as for test results, can also be stressful and taxing for patients.
Close-out conversation	While I am unaware of concrete data on this topic, my sense is that providers are pretty good at this when it comes to acute episodes (e.g., surgery, cancer treatment). While I'm sure there is room for improvement, this doesn't seem to be one of the bigger pain points that patients surface in surveys about their health care experience.

READ MORE

The end of prior authorization? →

PART FIVE

The end of prior authorization?

You may have noticed that prior authorization shows up as a common concern today but is not even mentioned in my magic wand scenario. That is because ***if*** we adopt the reforms recommended by Worthy, including the effective implementation of a broad, modern, artificial intelligence-powered, shared decision-making process, we can eliminate prior authorization while ensuring health care is affordable for everyone.

The primary basis for this belief is rooted in Wennberg's work referenced earlier. He and his team found that when patients understood their diagnosis and their treatment options and had an opportunity to discuss those options with their provider, they tended to choose more conservative (less costly) treatments, get better results, and be more satisfied.

Perhaps more importantly, this approach feels like a much more efficient, effective, patient-friendly, and physician-friendly way to fulfill the stated goal for prior authorization and other "utilization management" activities, which is to ensure that people are getting the right care at the right time and in the right place (bearing in mind that for many patients and physicians, these health plan processes don't feel like they are trying to achieve these goals). It also takes the decision-making out of the hands of health plans and puts it in the hands of the patient and their healthcare providers, while ensuring that decision is fully informed.

It is important to note that in order for this to work and for us to fully move to this vision, we will need to adopt a much broader set of recommendations beyond shared decision-making. Perhaps most importantly, this will require eliminating financial conflicts of interest that may motivate parties to recommend or provide care that is profitable but not always in the best interest of the patient. This broader set of recommendations is summarized in the chart below:

Worthy recommendation that must be adopted to eliminate prior authorization	Rationale
Every American has a comprehensive, real-time digital health record	This must exist for healthcare providers and their support tools to understand the full health history of each patient, and to make shared decision-making work. (See last month's Worthy segment "Digitize, Simplify, Automate").

Eliminate all forms of "spread pricing" for drugs	This eliminates the profit incentive for doctors, hospitals, and others to prescribe and administer a higher volume of more expensive drugs, irrespective of what is best for the patient.
Eliminate fee-for-service payment system and pay health care providers based on outcomes, patient satisfaction, efficiency	This eliminates the profit incentive for doctors, hospitals, and other caregivers to simply do more, as opposed to what is best for the patient. (Note that the specific recommendations for this will be included in next month's Worthy segment "Tie Payment to Healthy Outcomes").
Ensure prices for pharmaceuticals and other therapeutics are tied to the actual value of the drugs	By ensuring the price of a drug reflects its actual value, it should help make all therapeutics affordable while supporting ongoing innovation—and avoid the potential risk that eliminating prior authorization opens the door to big spikes in the volume of unaffordable drugs. (Note that the specific recommendations for this will be included in the July Worthy segment "Make Prescription Drugs Affordable").
Out-of-network pricing and utilization abuses must be addressed	There are currently some significant abuses of out-of-network pricing and utilization of services, largely driven by profit-seeking private equity firms, that if left unaddressed could create substantial cost without improving quality in a world without prior authorization. (We will discuss this in a future Worthy segment but in the meantime, see this New York Times article for examples).
Health plans must be able to set, communicate, and abide by clear rules (e.g., determining which providers are in-network, only covering drugs approved by the Food & Drug Administration)	In every profession, there will always be a small percentage of people and organizations that try to commit fraud and/or abuse in order to profit. Health care is no different. So, there will be a small percentage of physicians, clinics, and/or hospitals that try to abuse the "no prior authorization" world, and to combat this, health plans need to be able.

to respond (e.g., by deeming those providers as out-of-network and requiring prior authorization for out-of-network providers).

In addition, one of the practices that can add substantial cost without any evidence of improving health care is what is referred to as “off label” prescribing of drugs. This is when a physician prescribes a drug for a condition/ illness that has not been approved to treat by the Food & Drug Administration. Currently, Medicare does not allow insurers to cover these “off label” prescriptions and health plans need to be able to do the same. At the same time, we should allow for expedited clinical trials when there is a belief that a drug could be useful for a condition for which it is not yet approved. It is important to note that typically drug companies are not allowed to charge for a drug going through clinical trials, which should continue to be the case in these circumstances. (We will also discuss this in a future Worthy segment).

This may seem like a lot, but it is all very doable if we set our minds to it. More importantly, my magic wand vision for care Worthy of us all does not include prior authorization. In order to achieve that lofty ambition, we need to make all the changes necessary to put the full power of decision-making into the hands of patients and their caregivers. Of course, that requires a shared decision-making process that works, which is the subject that we turn to next.

READ MORE

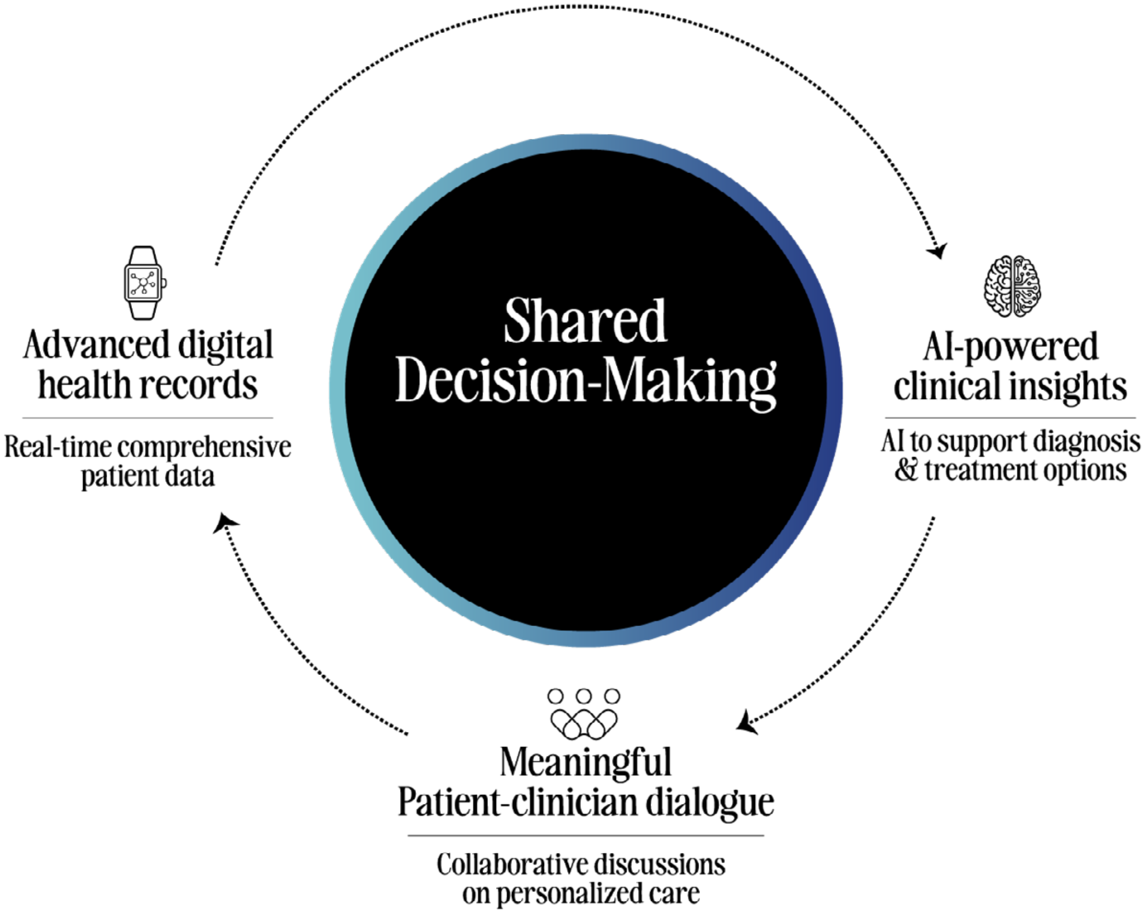
How to make shared decision-making a reality →

How to make shared decision-making a reality

As you can see from the diagram below, there are three basic elements to shared decision-making:

- A comprehensive, real-time, digital health record that can easily be accessed and used by the patient and their loved ones, e.g., easy-to-read synthesis of medical history
- An artificial intelligence model to assist in diagnosis and identification of treatment options
- An in-depth conversation between the patient and their treating clinician(s) to decide on the best treatment option

Elements of shared decision-making in healthcare



Since we covered the digital health record in the last Worthy segment, we will concentrate here on the last two pieces of shared decision-making.

Using artificial intelligence to support diagnosis and identify treatment options

As we noted in the Worthy segment "Overview and Current State of Health Care," the human body is incredibly complex, and the pace of discovery is beyond the capacity of any individual to understand, no matter how intelligent or well-trained. A study by PubMed in 2004 calculated more than 7,000 articles per month published in primary care journals that physicians trained in epidemiology would need to read to be fully up on all the latest research — a physically impossible 29 hours per weekday. Partly as a result, it is estimated that it takes about 17 years on average for robust clinical research findings to be incorporated into routine clinical care by 50% of eligible clinicians.

Put another way, no matter how good you believe your physician(s) is/are, they simply cannot know everything they need to know about what is available in the world for treatment options unless they use technology as an aid.

Artificial intelligence is perfectly suited for this kind of task because it is exceptionally good at summarizing large quantities of information for multiple audiences in multiple languages and discovering insights based on that information. We also know that artificial intelligence outperforms doctors on a lot of important dimensions, including providing an accurate diagnosis. Here are a few examples:

- A small study conducted by Beth Israel Deaconess Medical Center in Boston found that ChatGPT outperformed 50 human physicians when assessing six selected medical case histories to diagnose illnesses (NYTimes). Note that all examples and links are the same as in the artificial intelligence section of Digitize, Simplify, and Automate.
- Microsoft's AI (artificial intelligence) Diagnostic Orchestrator program correctly diagnosed 85% of medical cases described in the New England Journal of Medicine vs. about 20% for human doctors (Time).
- Another study published by Bioengineering found that GPT-4 turbo outperformed a sample of over 17,000 physicians internationally in general medical knowledge, except for pediatrics (PubMed).
- Given the pace that artificial intelligence large language models are progressing, by the time you read the bullet points above, it is a near certainty that the models are performing at a much higher level.

Beyond these facts, there is also the emotional comfort family and friends get from the confidence that no stone is being left unturned for the care of their loved one. For those that have endured caring for someone with a life-threatening and/or life-altering illness, they often carry the emotional burden of wondering if there is something out there that can make a difference but it won't be found (or won't be found in time). For these and other reasons, care Worthy of my loved ones definitely includes use of artificial intelligence to both aid in timely, accurate diagnosis and to provide treatment options as part of shared decision-making.

Of course, it is critical that we use it smartly and appropriately, including consistent with the criteria outlined in the last Worthy segment. To that end, the artificial intelligence models used to support shared decision-making must have the following characteristics:

- Provide objective, clear, fact-based options but do not make decisions. The decisions are left to the patient and their doctor(s).
- Be trained on and provide summaries of credible healthcare data. We do not want our artificial intelligence model throwing out a fringe theory posted on the internet, and therefore we need to limit the world it searches for diagnosis and treatment options to those that have a credible fact base.
- Make the logic or "chain of thought" completely transparent, including citing actual studies and evidence used to support findings, so that human beings can take a look for themselves and determine whether they agree.
- Continuously monitor performance, as would be done for any human being doing the same job. We know artificial intelligence makes mistakes. While this should happen less frequently than it does with human beings, it will happen and therefore we must constantly monitor, review, and provide feedback to these artificial intelligence models.
- Abide by all federal and state privacy and security laws and regulations. Artificial intelligence will have access to sensitive personal information that cannot be shared with those who should not have access to it.

READ MORE

Some examples →

Some examples

Let's take a look at a couple of examples, one hypothetical and the other real, in order to see how this vision might actually work in the real world.

Back to the future

About 8% of adult Americans, or approximately 16 million people, suffer from chronic lower back pain, most of whom have difficulty with mobility, self-care, social participation, work activities, and sometimes have issues with sleep, fatigue, and depression. In addition, a total of 65 million Americans report having some kind of recent low back pain. It is the most common cause of job-related disability with estimates starting at 80 million workdays lost per year as a result (Health Policy Institute, NCCIH).

For anyone who has experienced an episode of back pain, it can be incredibly debilitating and frustrating because we tend to use our back with nearly every kind of movement we make. Therefore, it can be extremely difficult to find relief and it is not surprising that those experiencing chronic back pain – along with their loved ones – can reach significant levels of desperation in search of something to improve their condition.

There are certain instances in which back surgery has demonstrated the ability to provide relief and made a huge difference in people's lives – and I know a few people for whom that has been true. However, as you will see below, there are many instances where there is not compelling evidence for back surgery as an effective treatment for back pain and it can even make things worse.

While this is probably intuitive to us all, the bones, muscles, nerves, and other tissues that make up our lower back are a very complex, interconnected part of our bodies. According to clinicians, it is also true that the spine often lacks the clean cause-and-effect found in other fields, in that imaging findings do not always match symptoms. Many people have degenerative changes without pain, and others report disabling pain without much, if anything, visibly abnormal.

This uncertainty means that treatment recommendations, particularly when it comes to surgery considerations, can become a "judgment call." Yet despite the uncertainty, the lack of supporting evidence for more back surgeries, and the significant potential risks associated with these surgeries, we've seen a significant increase in back surgeries over the last several decades.

Paula Aceves published an excellent article in New York Magazine on September 26, 2025 titled, "**The Spinal Surgeries That Didn't Need to Happen:** *As much as half of all spinal fusions don't alleviate pain — why do doctors perform so many?*" (NY Magazine)

In the article, she shares some heartbreaking stories of individuals struggling with severe and worsening back pain and loss of mobility and quality of life, in some cases after multiple spine surgeries. She also documents how spine surgery has become one of the country's most lucrative specialties, particularly when combined with the payments these surgeons receive for being "consultants" to medical device companies and/or using certain surgical implants.

She goes on to say that this may be a big reason why "rates of spine surgery are higher here (in the United States) than in any other developed country in the world — nearly double those of New Zealand, Australia, Canada, Norway, and Finland and about five times those of the U.K." All of this despite the evidence pointing to spinal surgery having "lackluster outcomes."

Some of the biggest critics of this phenomenon are disillusioned surgeons themselves. Eugene Carragee, former Director of the Stanford Spine Center and former editor-in-chief of *The Spine Journal*, is one example of this. Below is an excerpt about Carragee's work from the New York Magazine article.

"Throughout the aughts, he (Carragee) published many studies that prodded the consensus that spine surgery was a primary tool in the treatment of back pain, including one that found fusion surgery didn't help patients with ruptured disks heal faster and another arguing that in many patients, fusion surgery wasn't helpful long term compared with other procedures. 'To a large extent, a lot of my research was just trying to figure out how valid these other, more aggressive surgeries were from a medical point of view,' he said. 'Well, a lot of it was not very valid.'

It is also true that all surgeries, including back surgery, have inherent risks. People can have bad reactions to anesthesia, contract an infection, or experience complications from the pain management drugs they take after surgery (e.g., opioid addiction). The point is, any time surgery is a potential treatment option, it is important to understand the potential benefits as well as the risks.

I have a friend who likes to geek out on healthcare research and probably reads all of our Worthy "Nerd Alerts." He was having chronic lower back pain and visited with a back surgeon who recommended an invasive surgery. When my friend asked for the evidence behind this recommendation and the results other patients have had with this surgery, he was shocked by the physician's absolute refusal to provide any information and the insistence that because the doctor worked for a reputable hospital and health system, no such information was required. My friend immediately decided not to get the surgery and remains incredulous that this type of basic information is accessible for far less important decisions, but not for treatment as potentially life-changing as back surgery.

Given all of this, you might not be surprised to learn that back surgery is also one of the procedures that often requires prior authorization from health plans. In other words, the way we are currently dealing with this high volume of sometimes questionable back surgeries is for health plans to hit the pause button and require more information to justify the treatment.

Which brings me back to our proposed shared decision-making model. What would you want for your loved one if they were suffering from debilitating, chronic low back pain?

You would probably not want the current model which has too high a probability of resulting in a back surgery that potentially makes things worse, and/or a potentially unpleasant prior authorization process that may or may not help lead to the treatment option in which you have the most confidence. It seems to me that if the patient, their loved ones, and their healthcare provider(s) (not just a surgeon in this case) went through all the available evidence, and the pros and cons of pursuing various treatment options such as physical rehabilitation, acupuncture, nutritional changes, drug therapies, and surgical procedures, we would have a lot fewer unnecessary back surgeries. Rather, we'd get better pain management/reduction, and we'd have happier patients.

Of course, all of that information needs to be accessible and clearly communicated, and we need to pay the clinicians participating in the decision in a manner that they do not have a financial bias toward any particular treatment. But with all this in place, a shared decision-making model for lower back pain seems like a far superior approach to what is happening at the moment.

An inspiring, courageous story...and a reminder that we need to improve the system.

Aidan Brown is 20 years old and a four-time stage IV cancer survivor. He was first diagnosed with stage IV neuroblastoma a few days before his fifth birthday. By his own calculations, his health care journey and repeated recovery are exceptionally rare – perhaps one in every 2 million people.

Aidan and his mother, Michele Brown, describe their incredible healthcare journey in the video below. It was shared by Seema Verma, former Director for the Centers for Medicare and Medicaid Services (CMS) and current senior executive at Oracle, where she interviewed Michele on stage at Oracle's 2025 Health and Life Sciences Summit. Following the family video, Seema's interview is also available to watch on the video below.

> Please do watch this video as there is no way I can do their story justice by writing a summary. It is inspiring, courageous, and a revelation of what needs to change in our healthcare system.

Now that I've wiped away my tears, we can proceed. There are so many observations I have from watching that story, but the first is the power of love. Watching Michele consistently insist on finding a way to get Aidan access to treatment that will work and seeing him calmly and courageously battle through waves of intensive treatment was inspiring.

It also struck me how Michele was not just willing, but able, to support Aidan on his journey. While I don't know their specific circumstances, this had to effectively be more than a full-time job for Michele for long periods of time. Beyond the sheer persistence, determination, and emotional resilience required, it may also be more difficult for other parents to do what Michele did in different circumstances. For example, what if the next five-year old child diagnosed with this cancer is supported by a single parent? My point is that, based on what I was able to observe, Aidan's results were in part due to the truly extraordinary efforts of Michele and his family, which will not always be replicable for others.

Through her interview, Michele also highlighted issues that struck me as compelling reasons to pursue the changes we are advocating for in Worthy, including ensuring that everyone has:

- Health insurance coverage. Aidan contracting this rare cancer was a matter of chance. Even with insurance, the cost of all this coverage had to take a significant toll on the Brown family, however, facing this illness without health insurance would have financially crippled the vast majority of families in the country and left them with an impossible set of choices to make.
- A real-time, comprehensive digital health record, that includes all images and lab results and is easily accessible and usable. Clearly this would be vastly superior to the folder Michele had to carry around.
- Access to proper artificial intelligence support in a shared decision-making process to help make a timely and accurate diagnosis, especially for a rare disease. As you heard in Michele's story, there were a lot of doctor visits before the actual diagnosis, and by then Aidan was already at stage IV. Relying on your personal physician(s) to identify a case and in an unaided way, especially one that is rare, is not a recipe for success.
- Access to that same artificial intelligence support in a shared decision-making process to ensure knowledge of all the potential treatments available, including clinical trials. At one point, Michele found out about a clinical trial through a chance connection, of which the clinicians treating Aidan were unaware. Matching patients with potential life-saving or life-enhancing treatments should not be a matter of chance, and with rare diseases like this, we cannot expect our clinicians to be aware of all the possibilities.
- A simplified administrative experience. Michele talked briefly about the huge volume and complexity of the paperwork she received associated with Aidan's care. Clearly, we can and must do better on this front so that future parents can just focus on supporting their ailing child.
- Support for an intense healthcare experience. In addition to the coordination required for medical care, including preparations like travel booking and appointment scheduling, imagine the many tasks required of the family to support Aidan's health at home, including adhering to medication, dealing with potential side effects, and ensuring a sterile environment to reduce the risk of infection when the immune system is impacted by treatment, just to name a few. Patients and their family need proper support in these situations, so that they have the best chance at recovering without requiring a family member to make it their full-time job.

Perhaps most importantly, Aidan and Michele's experience points to the need for a shared decision-making model and everything required to enable it. While this is an incredible and inspiring story, care Worthy of us all should not depend on the extraordinary, heroic efforts of a family. It should be available to all of us, all the time.

READ MORE

What is next? →

PART FIVE

What is next?

So how do we make this vision a reality? Most of the things that need to happen require new laws and/or regulations to be adopted, including:

- Ensuring every American has a real-time, comprehensive, digital health record
- Moving physicians, hospitals and others off a fee-for-service payment model and instead, pay for outcomes
- Reforming the pharmacy distribution system and pricing to ensure the prices of prescription drugs are tied to their actual value
- Addressing pricing and utilization abuses by some out-of-network health care providers

Each of these reforms either already has been or will soon be proposed in a Worthy segment which means that we will have created a clear path to making this a reality soon. We then need to convince the powers that be in Washington D.C. to make it happen.

When it comes to creating the AI-powered critical insights and using it in a shared decision-making process, I believe this needs to come from the health care industry (physicians and health plans in particular). We might need help from the federal government in the future, however, given how patients are already using AI and how fast the technology is moving, it seems that the industry should be motivated and have the means to create this capacity on their own.

READ MORE

Most importantly, hang on to that magic wand! →

PART FIVE

Most importantly, hang on to that magic wand!

Care Worthy of us all is the highest of possible standards. We value the life and the health of those we love infinitely, and we expect the best for them when they need help. Envisioning the care model that meets this standard cannot be an incremental exercise. It demands full use of the magic wand described at the beginning of this segment. Of course, creating a healthcare system in which every eligible health interaction is personalized will not be easy, but it is possible. That said, there is a lot of work to do, so hang on to that magic wand!

THISISWORTHY.COM