

p.14 | **LIVER DISEASE ON THE RISE**

Learn why it's important for people with blood and bleeding disorders.

p.24 | **DIGITAL HEALTH**

As technology advances, the personal touch still matters.

p.30 | **VOICES FOR CHANGE**

Four blood and bleeding disorders advocates share their stories.

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REBRANDS

A New Name for a New Era

p.20

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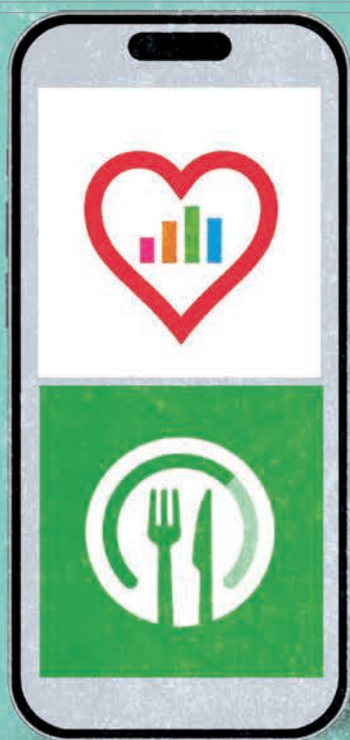
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Technology is making way for a more connect

WRITTEN BY STEPHANIE CONNER ILLUSTRATIONS BY PATRIC SANDRI



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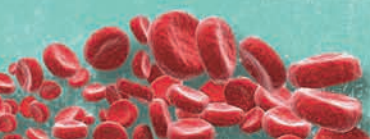
DIGITAL HEALTH

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LOOKING AHEAD: HOW AI CAN IMPROVE HEALTH CARE

Data is necessary to make health care decisions, but digital health is producing more than humans can handle. Physicians, for example, can receive tremendous amounts of data on a patient — the latest lab numbers, self-reported vitals, and more.

That's where advances in artificial intelligence (AI) are exciting.

"It's impossible for a person to look at thousands and thousands of data points and make sense out of it," says Roshni Kulkarni, M.D., a pediatric hematologist/oncologist. "But I think in the future it may be possible to have some kind of a technology look at and collate the data and give it in a form that people can understand."

Alex Krist, M.D., MPH, a family physician, sees opportunities to use AI to benefit patients as well, helping them process information from their doctor.

"I think AI has potential for that. We're just so new into that realm," he says. "The focus has been creating systems for clinicians, not creating systems for people to use, and we need to change that."

Roshni Kulkarni, M.D., recalls a time when a patient was attacked by a wild turkey and wanted advice about whether he needed to take his factor.

"He was 60 or 70 miles from me, so we did a telemedicine visit. And I could see he had a 6-inch laceration on his leg," she says. "Fortunately, he had just taken his factor the day before, and the injury site looked pretty dry. I brought in my infectious disease specialist, who said the patient needed a tetanus shot."

The ability to use a video screen and internet connection to deliver health care — called telehealth — can be useful in situations such as these, says Kulkarni, who is professor emerita in pediatric hematology/oncology and director emerita for the Center for Bleeding and Clotting Disorders at Michigan State University.

Telehealth is just one example of digital health, a broader movement in health care seeking to use digital tools to enhance the patient and provider experience. And from Kulkarni's perspective, there are many reasons to be optimistic about how it can help people with blood disorders access comprehensive care more conveniently.

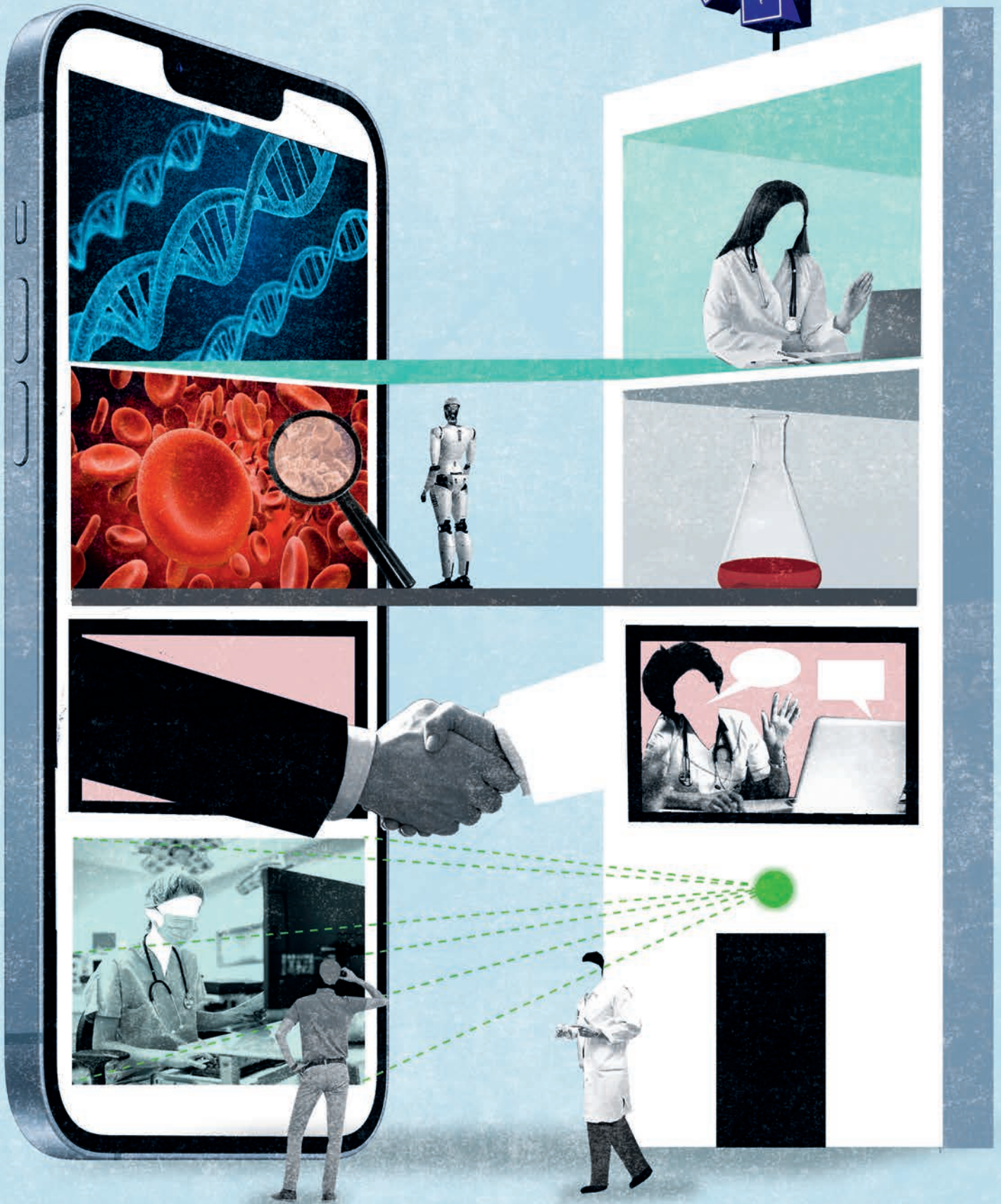
But questions remain: How do we overcome some of the challenges inherent in the digital experience? And how can patients and providers best use digital tools to enhance the quality of health care without diminishing the personal touch?

WHAT IS DIGITAL HEALTH?

One thing complicating conversations around digital health is how vast the landscape is. Digital health is "more than an app on your phone," says Kevin Perea, author of *The Digital Health Revolution* (2019) and founder of TranscendIT Health,

ESTABLISHING CONNECTION

The goal of digital health is to help people access comprehensive care more conveniently without diminishing the personal touch.



a consulting firm that specializes in digital health. “It’s really a means of connecting you to resources, whether they’re real or virtual.”

Digital tools can include electronic health records, patient portals, mobile applications, telemedicine platforms, data analytics systems, remote monitoring, wearable technologies such as smartwatches, and even artificial intelligence and chatbots.

“As a family physician, I think of digital health as tools that can help clinicians and patients better manage information, be connected, and act on information,” says Alex Krist, M.D., MPH, professor in the Department of Family Medicine and Population Health at Virginia Commonwealth University.

DIGITAL HEALTH IN ACTION

During the pandemic, many medical practices took advantage of telehealth technologies. For people who didn’t need to be seen in a clinic, it was safer and, in some cases, just as effective to have a conversation via videoconference.

For those with blood and bleeding disorders, regular check-ins with a doctor are important and can lead to better medication adherence, Kulkarni says. But for some people, in-person appointments can be a burden, so the ability to use telehealth can be advantageous.

One of the biggest benefits of telehealth is saving time and money, Kulkarni says. In 2016, she and a colleague published a letter to the editor in the *New England Journal of Medicine* describing their cost analyses. To travel to her clinic for specialty care, people racked up bills averaging around \$1,300 for hotel, gas, food, and time off work. A visit with a specialist using telehealth cost around \$40.

But telehealth isn’t the only application of digital health. For individuals participating in clinical trial research, digital platforms can provide the opportunity to answer survey questions or provide other data from home rather than driving to a clinical care site. This means more people — from various backgrounds and geographic areas — can benefit from new and experimental therapies.

People with chronic conditions also can use digital tools to monitor their health — reporting blood sugar or blood pressure levels or physical activity — and to communicate with their physicians.

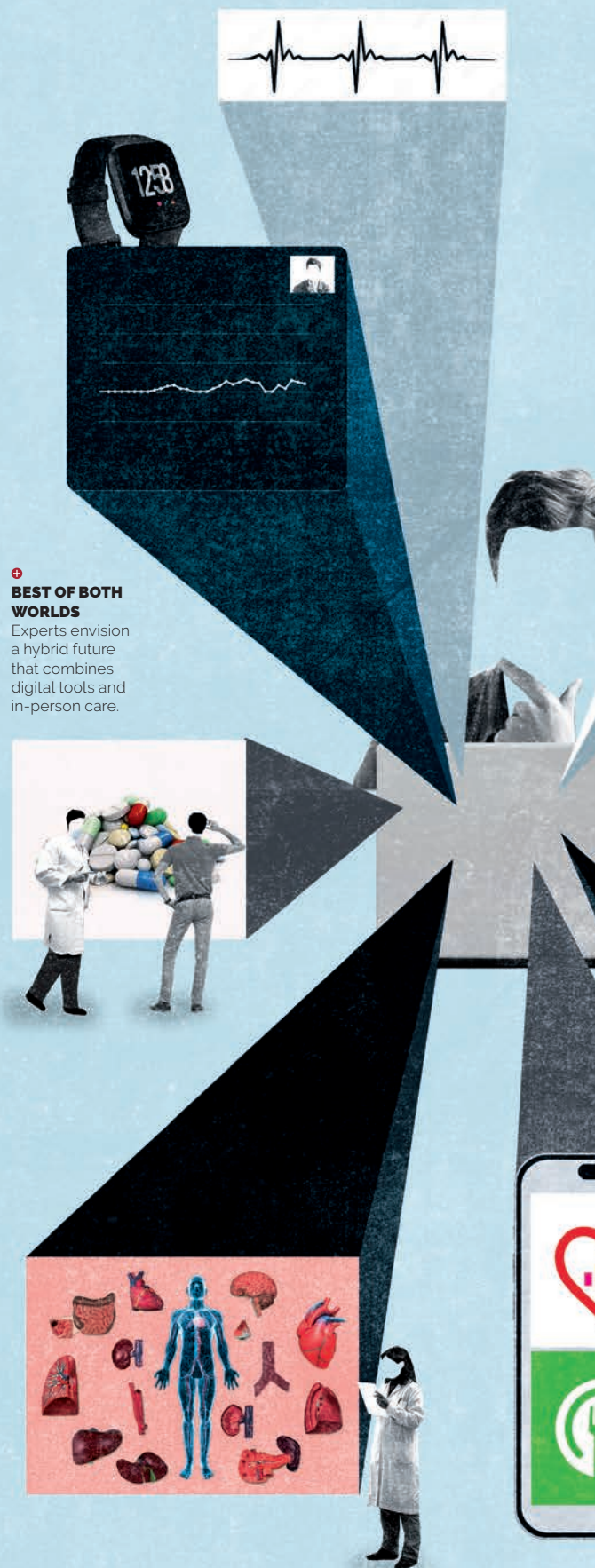
Being able to receive simple messages and educational materials — pictures of the exercises your physical therapist showed you during your appointment or written instructions for a medication — through your provider’s patient portal is another example of digital health tools at work.

THE CHALLENGES

With billions of dollars invested in digital health each year and digital technologies becoming more powerful and omnipresent, there are reasons to be hopeful, but there are also challenges.

For providers, Kulkarni says, “one disadvantage is you’re not touching and feeling the patient.”

Provider burnout is another concern that’s been compounded by digital health. A September 2022 study in *Mayo*



BEST OF BOTH WORLDS

Experts envision a hybrid future that combines digital tools and in-person care.

Q&A WITH LEONARD A. VALENTINO, M.D., DIGITAL HEALTH ADVOCATE

The National Bleeding Disorders Foundation (NBDF) believes digital health can provide numerous benefits for people with blood disorders. Leonard A. Valentino, M.D., president and CEO of NBDF, shares his thoughts.

WHY IS DIGITAL HEALTH AN IMPORTANT PART OF NBDF'S MISSION?

Improving access to care and achieving health equity are critical to our mission of enhancing the health and well-being of people living with inherited bleeding and blood disorders. Digital health strategies are important tools we can use.

IN WHAT WAYS IS NBDF SUPPORTING THE ADVANCEMENT OF DIGITAL HEALTH AND ADVOCATING FOR THE BLEEDING DISORDERS COMMUNITY?

Our Digital Health Priority Action Team was created to identify opportunities for NBDF to advance health equity using digital strategies. Plus, we are partnering with organizations like the American Telemedicine Association on advocacy and public policy issues to increase access to digital technology and overcome the digital divide (millions of Americans lack access to the internet or to mobile devices). We also hope to partner with hemophilia treatment centers interested in telemedicine and other digital strategies to improve access to care.

Clinic Proceedings showed that nearly 63% of physicians were reporting emotional exhaustion and other symptoms of burnout. Burnout is commonly associated with “system inefficiencies, administrative burdens, and increased regulation and technology requirements,” according to the American Medical Association. Corresponding with people via patient portals or taking on additional patients via telehealth can contribute to the overwhelm.

“And it’s not just physicians. It’s all health care providers — nurses, social workers, dietitians, everyone,” notes Kulkarni, who is also the former director of the Division of Blood Disorders for the U.S. Centers for Disease Control and Prevention.

Plus, while a lot of digital health tools are available, it’s uncertain that they are accomplishing their goals.

“It’s understanding what people need, and it’s also improving health outcomes, improving the care delivery process, and improving the health of the health care team,” Krist says. “We have to have data showing that doing these digital health things has all of those different improvements, and we’re not studying it enough to know that.”

KEEPING THE HUMAN CONNECTION

For patients and providers alike, maintaining human connections remains critical as digital health transforms. Pereau says digital companies learned an important lesson in the early 2010s: You can never develop a solution that is in lieu of a person’s doctor.

“Somewhere along the line,” he says, “the telehealth companies figured out that we shouldn’t be competing against the doctor. We should be helping doctors better connect and service their patients.”

Although people used telehealth options extensively during the pandemic, that trend is reversing course, Pereau adds, because people have a need to connect. “More people are coming in to see their doctor,” he says, “which I think speaks volumes about how people prefer to consume health care.”

But digital technology can help providers keep in touch with their patients when they’re not face to face. “I think it’ll always be a delicate balance,” Pereau says. “You get access to the best resource you can, in the shortest amount of time. Sometimes, that’s going to be in person. Sometimes, that’s going to be virtual.”

Kulkarni envisions a hybrid future: “Sometimes physical, sometimes virtual, but the whole idea is to provide care to the patient.”

The key, Krist says, is finding smart ways to use digital health tools. “When digital health is done right, it aggregates information and it allows people to connect as people,” he says. “Chronic care, like family medicine, should be grounded in a trusting, longitudinal relationship. Effective digital health tools need to build those relationships.”



HOW TO GET THE RIGHT TREATMENT FOR YOU: Whether it’s virtually or in person, health care is better when patients and providers work together. Read more about shared decision-making for bleeding disorders: hemaware.org/shared-decision-making