Smartphone app for heart health
Feedback for users, innovative tool for researchers

In March, the School of Medicine launched a first-of-its-kind iPhone app that enables users to help advance the understanding of the health of the human heart. The free MyHeart Counts app uses the new Apple ResearchKit framework to help assess each user’s heart health and provide information on how to improve it. The app represents an entirely new approach to medical research, making it easier for scientists to study health and disease by allowing them to gather real-world participant data through the iPhone.

The app collects data about participants’ physical activity using the smartphone’s built-in motion sensors. Participants also are asked to respond to surveys and questions relating to their cardiac risk factors and will get feedback on their chances of developing heart disease and an estimate of their “heart age.” Among other things, the researchers will study what factors motivate people to improve their heart health and will provide users with coaching tips. Michael McConnell, MD, professor of cardiovascular medicine at Stanford, is the principal investigator for the MyHeart Counts study.

Stanford Medicine’s MyHeart Counts is one of the first five apps to use Apple’s ResearchKit framework. With its release as open-source software in April, do you expect to see other researchers jumping onboard using this new platform?

Absolutely. One of the key academic goals of developing these ResearchKit apps was to make it much easier for other researchers to implement additional studies. This research “tool kit” Stanford and other institutions helped to develop includes doing consent, surveys and research tasks through a smartphone, which provides the building blocks for designing new research studies. Releasing ResearchKit as open source makes it easier and will help spread this kind of research to other phone operating systems.

Since the MyHeart Counts app was released in March, almost...
SoundBites

The Scientist

“What we’re looking forward to is showing that, in combination with current diagnostics, this will improve our ability to diagnose sepsis.”
— Postdoctoral scholar and surgery resident Timothy Sweeney, MD, PhD, on his study which could be the basis for a new diagnostic test for sepsis. May 14

If you look at mothers’ antibodies after vaccination they are pretty high for the first nine months; then within two years the antibody levels drop very low. That’s why the mother needs a dose for every pregnancy.”
— Yvonne Maldonado, MD, professor of pediatrics, on his study which could be shown—thateatingadietlow in dietary fiber will have a large negative impact on the microbiota. This case study also highlights how rapidly the gut microbiota responds to diet.”
— Justin Sonnenburg, PhD, associate professor of microbiology and immunology, regarding a study on the devastating effects of junk food. May 21

MENS JOURNAL

“This study further highlights what other scientists have shown—that eating a diet low in dietary fiber will have a large negative impact on the microbiota. This case study also highlights how rapidly the gut microbiota responds to diet.”
— Justin Sonnenburg, PhD, associate professor of microbiology and immunology, regarding a study on the devastating effects of junk food. May 21

KQED Radio

“We’re doing better with all these programs, but is it adequate? No. Every time a kid winds up in the ER with bad exacerbation of asthma, it’s a failure.”
— Paul Wise, MD, MPH, professor of pediatrics and health policy expert, on the statewide challenges of treating children with asthma. May 24

Using yoga to combat the effects of childhood trauma

Can a simple regime of yoga and other mindfulness practices have cognitive benefits for children suffering from post-traumatic stress disorder brought on by poverty and violence?
A team of scientists at Stanford is trying to find out.

The researchers are working with the Sonima Foundation, a nonprofit dedicated to children’s wellness, in testing the hypothesis among 800 third- and fifth-graders at the Ravenswood City School District in East Palo Alto.

During the four-year project, the students will participate in 45-minute wellness classes that will include yoga-based exercise, nutrition, coping skills and mindfulness instruction two to three days a week, said Victor Carrion, MD, director of the Early Life Stress Research Program at Lucile Packard Children’s Hospital Stanford, who is leading the study.

“We believe that it will improve these children’s ability to pay attention in school and emotionally regulate themselves,” said Carrion, who is also a professor of psychiatry and behavioral sciences at Stanford University School of Medicine. “Yoga can teach them to gain control over their bodies.”

Promising pilot program
Carrion led an eight-week yoga pilot program at the school district in 2012 and found that the third- and fourth-grade participants had lower social stress, were less likely to experience anxiety and depression, and developed better interpersonal relationships and self-esteem.

When a story about the pilot program was featured on a PBS NewsHour episode, representatives from the Sonima Foundation took note. The organization’s founders decided that they wanted to fund a full-fledged study led by Carrion.

“‘We thought this could be a really natural relationship,” said Russell Case, the Western region program director for the foundation, which has launched yoga-based health and wellness programs at schools across the country.

And while the foundation has done significant work in this area, Case said, “this is the most comprehensive study we’ve ever been involved in. As far as we know, no one has done this large a study for this length of time.”

Personal intervention
Ultimately, Stanford and the Sonima Foundation would like to determine whether this kind of intervention in a community can help traumatized children better regulate their emotions. He said they hope to see potential bullies learn self control.

John Rettger, PhD, director of the Mindfulness Program within Carrion’s group, is a clinical researcher at the School of Medicine and a yoga instructor who is collaborating on the study. He said that he believes the results will show not only that students can better regulate stress using the curriculum but also that they will do better scholastically and have fewer disciplinary problems.

Rettger said that students are taught proper protocol for lining up and going to their mats, practice breathing and relaxation exercises, participate in a short discussion about topics that range from gratitude to happiness and then perform 20 to 25 minutes of yoga exercises that focus on breath-synchronized body movements.

“It’s pretty incredible what the kids are able to accomplish in a short amount of time,” he said.

To measure results, Carrion plans to study sleep and brain patterns of many of the students taking part in the study and examine their cortisol levels.

SEE YOGA ON PAGE 5
When her son was diagnosed with a serious kidney and urinary tract defect, Cathy Draper struggled to find information about his condition. “At that time it was very difficult to get the information we needed—not only to explain the defect but to help us in making treatment decisions,” she said. “I did not have a place to go for scientifically based health information.”

That changed just a few years later, when she donated a kidney for her son’s transplant and helped a family member who had just been diagnosed with ovarian cancer.

“By that time I had heard about the Stanford Health Library,” said Draper, a dental hygienist who has been a volunteer at the library for the past 20 years. “It was an invaluable resource while I researched both the medical conditions I was dealing with. Patients are often overwhelmed with difficult choices or complex diagnoses. I know only too well the need for trustworthy resources so that people can better understand their condition and treatment.”

The Stanford Health Library, which celebrates its 25th anniversary this year, is a free community resource for medical and health information. Started in a small storefront in the Stanford Shopping Center, the library’s main branch now is housed in the Hoover Pavilion, a landmark art deco–style building that was restored in 2012.

The library is open to all members of the community and offers extensive health and medical resources in multiple formats and languages.

Renovation challenges

The 2,244-square-foot library, located in what was the main lobby of the former hospital, boasts 14-foot ceilings, fluted columns and expansive windows that had been hidden behind drywall. Its stairway entrance is of high-quality terrazzo, a polished composite handmade by mixing stone particles into concrete.

Originally the first floor of the building held the emergency room, kitchen, labs, morgue and locker rooms for staff. The stairs led to the formal front door on the second floor, where visitors could wait in a reception area before being allowed in to visit patients. Over time the role of the building changed, as did public taste. Though the exterior did not change dramatically, a major renovation in the early 1960s removed most of the deco elements from the interior.

“There was not much to save inside,” said George Tingwald, MD, AIA, a credentialed architect, surgeon and director of medical planning for the adult and children’s hospitals. “The exterior did not change dramatically, a major renovation in the early 1960s removed most of the deco elements from the interior.”

See Health Library on page 6
40,000 users have downloaded the app and consented to participate in the study. How does this time frame and number of participants compare with recruitments for medical research trials in general? What do you hope to see in the future?

There have been larger research studies, particularly national efforts to study populations, but we believe enrolling this many participants in such a short time frame is unprecedented. We very much appreciate the interest in the public for participating in medical research and are excited to offer this new approach that clearly facilitates participation. For the future, we hope to learn from our research participants—from both their feedback and their data—on how best to engage with them and learn the most from our research.

Participants are asked to keep their iPhone with them as much as they can during a seven-day period that measures their physical activity. What happens when the participant cannot keep the phone on them during activities such as swimming?

The iPhone has a motion chip and sensors that measure activities but only if the phone is with you. The MyHeart Counts app captures these data, plus checks with you daily [during the seven-day assessment] to enter any activities that were not captured by the phone. While you only need an iPhone to participate in MyHeart Counts, the app does collect activity data from wearable devices that are linked to the app on the iPhone, including the Apple Watch.

Could you discuss the significance of the consent process for the future of medical research?

We believe this new “e-consent process” gives the participant study information in a more user-friendly way as well as more time to review and decide. These are critical elements to “informed” consent, but we will need to understand in more depth how participants respond to this format. The goal is to broaden the ability for people to participate in medical research in which they are interested. We greatly appreciate the efforts of John Wilbanks from Sage Bionetworks in working with all the institutions involved in ResearchKit to develop this consent process, as well as the input from our own bioethics group and Institutional Review Board.

How are you ensuring that participants stay anonymous and that data won’t be hacked or fall into the wrong hands?

We follow the best data security protocols, such as encrypting the data as it leaves the phone and using a secure server to receive the data. Also, personal identifying information is separated from the research data so that only anonymous data goes to a special secure server for analysis. While we employ all these security measures, we simply cannot guarantee that any system is 100 percent foolproof.

When the app was first released, it was announced that behavior modification methods would be studied. When do you expect this phase of the app to be rolled out, and what types of methods will be used?

Healthy behaviors are critical to preventing heart disease and stroke, so the MyHeart Counts app will study which motivational tools are most helpful. This will follow the second activity and fitness assessment, which occurs after three months. The initial approach will provide personalized feedback about individual behaviors and risk based on the American Heart Association’s “Life’s Simple 7” guidance.

Will the MyHeart Counts study be available on devices other than Apple’s? Could the platform be open-source software?

The open-source release of ResearchKit will certainly speed the ability to provide MyHeart Counts and similar research studies on other smartphones. We estimate that will occur in late 2015 or early 2016.

What kind of advice would you give to other researchers attempting to use this new platform for recruitment for medical research trials?

There have been technical bumps in using a smartphone app for research—one of the challenges faced by the first group of ResearchKit apps. We actively listen to user feedback and have made improvements to the app; future researchers will benefit from what we’ve learned. The main advice I would give to other researchers is to be straightforward with your participants that there may be technical issues, even for the next generation of ResearchKit apps, and to ask for feedback to help improve the technology as this new approach to research continues to evolve.

Leading the revolution in Precision Health

Learn how Stanford Medicine combines scientific innovation with progressive technologies to provide individual, compassionate care through its two world-class hospitals and network of providers:

medicalgiving.stanford.edu/precisionhealth.html
W hen the new Stanford Cancer Center South Bay opens its doors in San Jose for its first patients, Tracey Laney will be there waiting. For nearly 20 years, Laney has been one of the first people to greet patients at the Southbay Hematology Oncology Partners clinic in Campbell. The longtime practice now has joined with Stanford Health Care to form the new Stanford Cancer Center South Bay, which will welcome patients this summer.

“One of the first things our patients have asked us about the new cancer center is, ‘Are you going to be there?’” said Laney, a clinical administrative assistant. “We’ve developed relationships with patients—and that’s an important thing for them.”

The new four-story, 70,000-square-foot center brings together a familiar, community-based cancer clinic with Stanford Health Care’s high-level, comprehensive services.

“As the incidence of cancer grows and more and more people are being diagnosed with cancer, Stanford has wanted to take its expertise beyond the main campus,” said Sridhar Sesnadri, vice president of cancer services. “We saw the Southbay Hematology Oncology Partners as a perfect marriage. Many of the physicians are Stanford-trained, they’ve been in practice for many years, and they have a strong reputation. And we wanted to learn from them as we bring our practice to the community.”

The new center, located near Highway 85 and Los Gatos Boulevard, will offer the full range of services available through an academic medical center, including access to clinical trials, specialized imaging and tumor boards, in which a wide range of specialists confer on individual cases. The building will house two operating rooms for both complex procedures and same-day surgeries, such as lumpectomies and simple mastectomies, said nurse coordinator Catherine Kelly, RN.

“For breast cancer patients, we’ll be able to provide care from mammography all the way through survivorship in one location—right in their own community,” Kelly said.

The new four-story, 70,000-square-foot center brings together a familiar, community-based cancer clinic with Stanford Health Care’s high-level, comprehensive services.

Stanford is applying a new philosophy of cancer care in the center, with patients, staff and physicians all providing input on the building’s operational and physical features, as well as its patient-centered culture. Stanford’s Patient and Family Advisory Council, which includes members from the South Bay community, provided recommendations such as features to reduce the number of steps and stops that patients will make in the course of a visit; a tracking system to tell nurses if patients have been waiting in an exam room for more than 10 minutes; and a universal, one-time registration system to eliminate repeated check-ins as patients move from one location to another. Members of the advisory council also interviewed all new hires at the center to ensure a patient-friendly environment.

“We are making patients and their needs our highest priority,” said Kate Surman, administrative director. “We are shaping the culture at this new center so that everyone, even those who are not directly involved in patient care, understands the importance of—and is recognized for—their role in patient care.”

The building also minimizes the need for patients to move between floors by consolidating services. The fourth floor, for example, will contain a clinical lab, an infusion treatment center, a pharmacy and the medical oncology clinic. Support services will be arranged so that patients won’t have to travel elsewhere to attend a support group meeting or to talk with a social worker, nutritionist or member of the palliative care team.

H e said he expects that the wellness curriculum and regular yoga will help these children sleep and concentrate better. A lot of kids suffering from stress and anxiety have trouble focusing in the classroom.

“Yoga increases blood flow, which helps muscles relax,” Carrion said. “For many of these children there are triggers and cues. Physiologically, yoga helps them even out.”

The students, who began participating in the study in March, will be compared over three years with a control group of students in the Orchard School District in San Jose who have similar socioeconomic backgrounds but who won’t be taught the same curriculum. In 2018 the team will begin to analyze its results.

Ravenswood superintendent Gloria Hernandez-Goff, PhD, said the Sonima Foundation includes funds for 14 yoga instructors to teach the curriculum to every grade in all seven of the district’s schools.

"I expect it to have a huge impact on our students' academics,” she said. “I think their retention and focus will be higher and their behavioral problems will diminish. They’ll also learn self-discipline, self-control and how to use their energy in a positive way. This could make a difference in their lives.”

Upcoming issues will have more updates on the cancer center’s progress.
LEARN MORE ABOUT YOUR HEALTH
Events are free unless otherwise noted. Space may be limited, so please call to register in advance.

Living Well with Chronic Conditions
Date: Tuesdays, through July 7, 1:30–4 pm
Location: Stanford Health Library, Hoover Pavilion, 211 Quarry Road, Palo Alto
Registration is required. For more information call 650-725-4137 or e-mail pesimon@stanfordhealthcare.org. To register, call 650-498-7826.

Smart Sendoffs: Off-to-College Health Guidance for Students and Parents
An interactive learning experience for high school students and their parents on how to manage health issues at college
Speakers: Faculty, Stanford Division of Adolescent Medicine
Date: Sunday, June 28, 2–5 pm
Location: Li Ka Shing Center for Learning and Knowledge, 291 Campus Drive, Stanford Medical School campus
Fee. Register online at classes.stanfordchildrens.org.

Diabetes Support Group
For people with type 1 or type 2 diabetes
Date: July 8 and Aug. 12, 6 pm
Location: Stanford Health Library, 211 Quarry Road, Suite 201, Palo Alto
For more information, contact 650-380-3159.

Preparing for Multiples
A class for those expecting twins, triplets or more
Date: Sunday, July 19, noon–4:30 pm
Location: Community Programs Classroom, 4100 Boughannon Drive, Menlo Park
Fee. Register online at classes.stanfordchildrens.org.

Grandparents Seminar
Date: Monday, Aug. 3, 6 pm
Location: Community Programs Classroom, 4100 Boughannon Drive, Menlo Park
Fee. Register online at classes.stanfordchildrens.org.

Dads of Daughters: The Joys and Challenges of Raising Teen Girls
Speaker: Julie Metzger, RN
Co-founder, Heart-to-Heart Program
Date: Thursday, Sept. 17, 7 pm
Location: Community Programs Classroom, 4100 Boughannon Drive, Menlo Park
Fee. Register online at classes.stanfordchildrens.org.

Hoped to uncover the plaster murals and handmade metalwork shown in archival photos and architectural plans. But these features, as well as the original terrazzo floors, had been all but demolished in the 1960s redesign.

“Our goal was not to re-create the 1930s but to take elements of that style and develop it for continuity. We brought in materials to support the look without trying to replicate the original design,” Tingwald said.

“While the outside was meticulously restored, we approached the lobby with a sense of adaptive reuse. The Health Library was the perfect fit.”

The designers eliminated several small rooms to open up the space and fabricated new columns to match the ones outside.

The library staff respond to about 600 requests a month, with most inquiries revolving around cancer, aging, nutrition and chronic conditions like diabetes, arthritis and heart disease. Requests come in by phone, by e-mail and in person, with the library’s resources available to anyone in the community—not just patients and their families, Cain said. Librarians and volunteers also work closely with several Silicon Valley companies’ wellness programs.

“I’m amazed how different it is now,” said Laura Markman, who has been a library volunteer for 17 years. “I remember this spot as the hospital lobby, so it’s wonderful to me that it is still being used by the public. There are no space issues here, and it’s easy to sit right next to a patron to help them learn how to use the computer or navigate a website.”

The new location also allows the library team to work closely with the Stanford Coordinated Care clinic, located on the building’s fourth floor, where clinicians treat patients with chronic conditions. “It’s a model of integration with clinical care that lets us develop aspects of our collection and offer self-management classes that address the needs of these patients,” Cain said. “We hope to expand that model to other specialties. A resource like this is especially important at a place like Stanford, where treatments may be groundbreaking.”

Learn more about the Stanford University Medical Center Renewal Project at sumc renewal.org.
Implanted pump helps heart-failure patient graduate from high school

In February, Tovi “TJ” Balliao and his family received devastating news: The 17-year-old was suddenly in heart failure, experiencing life-threatening bouts of irregular heart rhythm.

“He seemed normal, laughing with his siblings, but doctors told us, ‘He’s like a switch. At any time he can turn off,’” said TJ’s father, Marlon. “We were so overwhelmed,” said his mother, Divina.

The diagnosis, severe dilated cardiomyopathy, often strikes without warning or any apparent trigger. TJ needed a new heart but was too sick to wait for a heart transplant.

“The wait time for a transplant was much longer than we could expect TJ to be stable,” said David Rosenthal, MD, a cardiologist at Lucile Packard Children’s Hospital Stanford and Stanford Children’s Health.

So TJ received a ventricular assist device (VAD), a pump surgically implanted in his heart to help it move blood through his body. At first, the Balliao family thought the pump would keep TJ alive until a donor heart became available. But the device enabled him to recover so strongly that doctors gave him an unusual option: He could go home with his VAD and delay a transplant indefinitely.

Extending lifespan

For TJ, a high school senior, this meant a precious opportunity to graduate with his class. For his doctors, it extended the vanguard of treatment for children with heart failure. Although some adult heart-failure patients now live with VADs for months or years, children who get the pump usually receive a transplant as soon as possible. Rosenthal thinks TJ’s case could represent a change in thinking.

“It’s possible that using a VAD to intentionally delay a heart transplant could add to the patient’s total lifespan,” said Rosenthal, who directs the hospital’s pediatric heart failure and transplantation program and is a professor of pediatrics at Stanford University School of Medicine. “Survival after transplant is not as long as the natural lifespan, especially for children.”

The VAD program at Lucile Packard Children’s Hospital Stanford is the largest in the country, with a number of different mechanical support devices in use. These devices help patients maintain strength while waiting for a new heart; otherwise, heart failure weakens the body, making recovery from eventual transplant more difficult. When a child is stabilized by use of a VAD, the medical team also can be more selective about choosing the best-matched donor heart. “There is some likelihood that a small proportion of patients’ hearts will be able to recover, and those children will avoid transplant completely,” Rosenthal said.

Device improvements

Rosenthal’s forward-thinking approach continues a long tradition of leadership in VADs from his team at the hospital’s Heart Center. In 2004, the Stanford Children’s Health team was the first in the western United States to use a VAD to help a child survive to transplant by pioneering a device called the Berlin Heart to help an infant live through a 55-day wait for a new heart.

The Berlin Heart was large and cumbersome, requiring children to live in the hospital. In contrast, TJ has a portable device called a Heartware HVAD, with a messenger-bag-style battery pack that he wears when he’s not near an electrical outlet.

“It’s cool: It tells me when it needs me,” TJ said. “It beeps to remind me to change the battery every six to eight hours.” He numbered the machine’s four batteries to ensure that he’s always charging and using them in a strict rotation, one of many tips he received from Jenna Murray, RN, the hospital’s VAD coordinator.

“He’s very organized; he did that himself,” said TJ’s mom. “He also knows all his medications, and he’s the one who fills up his pill box. He’s pretty responsible.”

Although life with the VAD comes with restrictions—no swimming, for instance—it’s a huge improvement on the early days of TJ’s illness, when his failing heart confined him to the hospital.

“I feel a lot better,” he said. “I can walk better, and that feels great.”

Future options

“TJ is pretty adaptable,” said Rosenthal, glad to be able to offer his patient the opportunity to finish high school on time, when the medical team and the Balliao family will assess the next steps.

TJ has been accepted to San Jose State University to study civil engineering, so he may be sitting in introductory engineering classes next fall with his trusty Heartware battery pack at his side. Perhaps he’ll receive a newer VAD with an internal power source to free him from his 24-hour tether to a battery or wall outlet. Such devices, Rosenthal said, are not far off.

“I like the idea of keeping that kind of option open for him,” Rosenthal said. “Our team is grateful to be on the forefront of expanding choices for kids with heart failure.”

“It’s possible that using a VAD to intentionally delay a heart transplant could add to the patient’s total lifespan.”

David Rosenthal, MD
Adding a patient-friendly touch to new neuroscience building

I moved from Boston to San Carlos in 2011 to be closer to my three children here in the Bay Area. I knew few people here and wanted to establish myself in the community, so I became an usher at the Bing Concert Hall and began teaching art in an after-school program. I also signed up for an evening class on brain health offered by Stanford’s Continuing Studies program, not realizing then how much that class would impact my life.

After the class, I asked the instructor, a Stanford clinical psychologist and neuropsychologist, about my shaking left hand. He suggested I make an appointment with Helen Bronte-Stewart, MD, a professor of neurology who directs the Movement Disorders Center at Stanford Medicine. She immediately diagnosed my shaking as Parkinson’s syndrome and spent some time explaining what I might expect. I was shocked and upset.

I was invited to join a support group for women with the disease, fondly nicknamed the “Parkinson Princesses.” I appointed myself as “culture chairlady,” which translated into group visits to museums and architectural gems like the Frank Lloyd Wright-designed home on the Stanford campus. I had attended the 30-member panel, which also included physicians, nurses and other staff.

I began working with the team in September 2014, helping to improve the experience for neuroscience patients, including those with Parkinson’s. The four-story, 92,000-square-foot building brings together all outpatient neurology services to create a one-stop destination for patients.

Our team focused on the design of a centralized check-in area to provide a seamless, efficient and harmonious service for patients entering the building for their appointments. The building includes other special accommodations for patients. For instance, a dark room will be easily accessible for migraine patients who need dim light and quiet to calm their symptoms. Interior colors will be subdued, and light fixtures will be dimmable to relieve acute light sensitivity in many patients. The building also will have on-site infusion stations for patients with multiple sclerosis, brain tumors or neuroendocrine disorders so they can visit their doctors and receive treatment in one location.

I am thrilled to participate in the neuroscience world at Stanford and to know that I have a future volunteering in areas where I can make a difference. My past experience as an interior designer has allowed me to participate in Stanford care and make a contribution.

—Nancy Stohn has been a feng shui consultant, interior designer, space planner and art consultant and has designed interior spaces for businesses and residences across the country.