

Health care in your hand

MyJourney Compass program puts cancer patients in control

By Alan Riquelmy
Staff Writer
ARiquelmy@RN-T.com

The future of health care might rest in the palm of your hand.

That future — a tablet computer — already sits in the hands of several Rome and Floyd County breast cancer patients. They're part of the MyJourney Compass pilot program that allows them electronic access to health records on a device that can fit in their purses.

"It's just cutting edge," said Gena Agnew, president and CEO for the Northwest Georgia Regional Cancer Coalition. "We are breaking new ground here. It's going to make such a huge impact."

The Nexus 7 tablets with 7-inch screens enable patients to access their health records regardless of their location using applications, or "apps," installed on the high-tech machines. It also removes the need for patients to carry stacks of paperwork. Reports related to their health care are literally at their fingertips.

Another first for the new technology is the ease with which patients can access their records from multiple health care providers such as Floyd Medical Center, Harbin Clinic and Redmond Regional Medical Center. In the past, someone would need to visit a facility in person to get copies of their records.

Now they push an icon on their tablet.

"It's electronic and at your fingertips," said Angie McWhorter, chief information officer of Harbin Clinic.

History

The MyJourney Compass program developed from discussions that began some three years ago, said Philip Lamson, senior health care consultant at Georgia Tech and the project director for the program.

Lamson was then with the Georgia Cancer Coalition, and researchers were examining the experiences breast cancer patients had with their treatment. The researchers discussed what gaps existed in that experience, and how they could be filled.



Philip Lamson

Please see COMPASS 3A

RN-T.com

Read these reports online for links to websites for Health Vault, Northwest Georgia Regional Cancer Coalition and Cancer Navigators.

• Compass to tomorrow 2D

An easier journey with the tablet

By Lauren Jones
Staff Writer
LJones@RN-T.com

When Koren Sinnock found out she had breast cancer in February, among the slew of emotions coursing through her mind at the life-changing news was the dread of an overwhelming amount of medical paperwork the 39-year-old couldn't quite face.

"At every appointment you go to the first few days, you get a whole stack of papers to go through, a whole new stack of books, bags, pillows. ... it's overwhelming," Sinnock said. "I went home and shoved it all in a bag and put it in the closet. It was just too much."

But Sinnock, who was the first out of more than 25 cancer patients to use the Google Nexus 7 for the MyJourney Compass program, was able to put her mind at ease once she entered her pass code into the tablet and a world of helpful information was resting in her palm.

"It's been wonderful," she said. "The first half of my journey, I didn't have the tablet so I had to find things on the Internet and try to sift through all the things they give you. The second half, I've had the tablet and it's been wonderful because everything is at your fingertips. All the questions that you have — just random questions — most likely there's something (on the tablet) that addresses that already. It's been really good for that."

The face of a federal program

Sinnock said when she first was approached by Cancer Navigators personnel to be a member of the MyJourney Compass advisory committee, she wasn't sure what she was getting herself into.

Please see TABLET 2A

LOCAL



Lauren Jones / Rome News-Tribune

Koren Sinnock (left), the first cancer patient to use the MyJourney Compass Google Tablet as part of a federal program being

launched in Rome, learns some useful apps on her Nexus 7 from Katie Weisbecker, education navigator for Cancer Navigators.

TABLET from 1A

"I really didn't know what it was," she said. "They started talking about it, and I just couldn't believe that Rome was the pilot for the country. I just think that's wonderful. Our small little town is a part of something so big, and for me to be a part of it. ... I think that if it could help one person, even someone my age who is computer savvy but doesn't even know where to start, this is a comfort to them."

The MyJourney Compass pilot program essentially enables patients to access their own health records as well as provides pertinent information about their diagnoses and treatment.

By using different apps, patients can pull up their records through Microsoft Health Vault, track their symptoms, record journals, track doctor's visits, look up medical terms and even read eBooks during chemotherapy.

And this is only the beginning. The program could very well change how cancer patients go through their journeys in the future.

Katie Weisbecker, education navigator at Cancer Navigators, said that personalizing each patient's tablet with documentation they need has helped calm a lot of women.

"Our nurse navigator goes in and does an assessment of what resources they might need," Weisbecker explained. "We're actually able to customize what's on (the tablet) so they're not overwhelmed, they won't get scared thinking they have lymphoedema, or inflammatory breast cancer, when they don't."

Weisbecker said tablet users can log what their medicines are so they have that information on hand. There are also nutrition apps so patients can keep track of their food intake and some stress relieving apps for those overwhelming moments.

Sinnock discovered her cancer herself and described the shock of being diagnosed. "I was caught off guard. I'm just 39, I hadn't had a mammogram yet," Sinnock said. "I was going to get one in September, but I'm glad I didn't wait. I'm glad it was something I was able to feel and know ... being under 40, I just didn't expect it. I don't have a family history of it."

Tablet taking edge off fear

The tablet, she explained, took the edge off the daunting amount of information looming over her and Sinnock said all the apps are helpful.

"The dictionary app has been great, I wish I'd had that earlier," she said. "Because in the first part when you're learning all the different stages, the doctors speak — I have wonderful doctors — but they get on a roll and they start talking and you're like, 'Oh my God, what are they talking about?' It helps to record it and then go back and pull up my dictionary out and figure out what they're talking about. Having that tool is very cool."

With information provided by credible sources, Sinnock said she doesn't scare



Contributed image

This screenshot from the resources page on the tablet shows cancer, nutrition and stress-relief apps that patients can use during their journey. It includes a Resources folder with downloaded PDF educational documents pertinent to the specific patient's condition, as well as bookmarks for Microsoft HealthVault and other credible health websites. The patient's cancer care providers and navigators are also on the page and by tapping their photos, they can access contact information immediately.



herself by searching the Internet and finding situations that don't pertain to her.

Another perk is being able to go on vacation and not having to worry about getting sick and visiting a doctor who may be foreign to her journey.

"Having all your records accessible, so you don't have to go into it from start to finish. ... it's also hard to remember every medication or treatment you've had, every visit you've had, it's hard to remember all that," she said. "It's nice to have it right there with you and to have (the doctors) pull it up and understand that. It's a really good feeling."

With Weisbecker available for guidance and training when it comes to the tablet, even those patients who feel they are not technologically savvy can learn the easy-to-use tool.

"If one person could read this article and say, 'OK, I'll try it,' especially if they've said no to it already or if they thought it would be something else they had to deal with, because it's such a great tool."

COMPASS from 1A

The cancer coalition and Georgia Department of Community Health then partnered with local health care contingent and applied for a \$1.7 million federal grant, called the Consumer Mediated Health Information Exchange Challenge Grant, to create the patient-centered program.

"The project is funded by the federal government's Office of the National Coordinator for Health Information Technology (ONC) through an award to the Georgia Department of Community Health (DCH), which engaged Georgia Tech to coordinate the project. It is one of 10 Challenge Grants that were awarded nationally and one of two that address consumer engagement," stated Kelly Gonzolez, chief of DCH's Division of Health Information Technology.

Agnew credits the ability of local health care providers to collaborate as one reason the community got the grant.

"They immediately thought of Rome, particularly because of our cooperative spirit among our health care facilities," Agnew added.

Teams began to discuss the best way serve patients. Agnew said the group first thought patients would use desktop computers to access their records. They then changed their plan to laptop computers.

iPads cost close to \$1,000 some two years ago when the team discussed what technology should be used, Lamson said. Prices have since dropped, which led to the choice of tablets for the program.

"Someone made the suggestion—what about tablets?" Lamson added. "They're very portable."

During those discussions the Georgia Cancer Coalition reorganized, Lamson said. Part of the former entity is now with the Georgia Research Alliance. Another part merged with Georgia Tech, where Lamson now directs the grant for MyJourney Compass.

Collaboration

One challenge with health records is the difficulty in getting them from one doctor to another in a different facility.

Health records and documents related to cancer can fill shelves in some cases. Carrying that much paperwork can prove daunting.

In FMC's case, health records are kept at the hospital and are requested by the patient when he or she wants a copy, said Jeff Buda, chief information officer with the hospital.

"There's a whole release-of-infor-

mation process," Buda added. "It wasn't anything automatically being pushed to the patient."

Redmond and Harbin Clinic have similar processes when patients want copies of their records. McWhorter said Harbin patients can log onto an online patient portal to access their records.

But that still required the patient to physically visit the other health care facilities he or she frequented or log onto their online portals to get all the documents.

The goal for local hospitals was to make their records available in an electronic format patients could access from their tablets.

"We all were working on how to provide the data to the patient," McWhorter said.

That led the project group to Microsoft HealthVault, a cloud-based technology. In this case, the "cloud" means a patient's records aren't on his or her computer's hard drive. Instead, they're stored securely by Microsoft HealthVault, and can be accessed through the Internet on a MyJournal Compass tablet.

A patient can access the records on the tablet regardless of his or her location if they have an Internet connection, and then show those records to the appropriate health care provider or caregiver.

"By putting all this in the hands of the patient, they mediate where it goes," Lamson said. "You're making the patient the custodian of the information."

Brad Treglown, Redmond director of information technology and services, said the tablets provide more access to patient records and speed up a patient's ability to get those records.

"MyJourney is a work in progress," Treglown said. "It's developing something that's not been done before."

How it works

Cancer Navigators is a nonprofit group that helps cancer patients through their journey of treatment. In the case of the MyJourney Compass, breast cancer patients are introduced to the technology and asked if they want to participate, said Charlotte Atkins, Cancer Navigators' executive director.

Lamson said he sees a patient's control and responsibility over their health care as a possible solution to health problems.

"Patient engagement is critical in my mind," Lamson said.

Dr. Matt Mumber, a radiation oncologist with Harbin Clinic and head of the hospital's integrative oncology program, agrees.

"MyJourney Compass is a tool giving patients access to some of their health information and facilitating secure communication between them and their cancer care providers via mobile technology," Mumber said.

Creating collaboration between health care providers and patient is key to Ann Hook, Redmond's oncology service line director.

"This initiative strives to use the latest technology to maximize collaboration among all care providers while empowering the most valuable partner, the patient," she said. "Interoperability is a key ingredient to safe, effective patient care. Redmond is excited to be a part of creating a more patient-centric approach to oncology care."



Jeff Buda



Angie McWhorter



Brad Treglown



Dr. Matt Mumber



Charlotte Atkins

LOCAL

Those who show interest are connected with an education navigator. The patient is enrolled in the program, and trained to use the tablet and technology.

Cancer-related apps are installed on the tablet. They also get access to educational material that's customized to their diagnosis, Atkins said.

"We're able to sit down and do one-on-one training on the tablets," she added.

The tablet's apps perform various functions, such as providing access to health records and keeping track of their medication and appointments. There are also apps that let patients communicate with their health care providers and track their symptoms.

"Many patients say they feel OK when asked by a doctor," Agnew said. "They won't say, 'at 3 p.m. I had bad pain. At 10 a.m. I felt OK.' The symptom tracker app will show when those symptoms spike. It's helping the patient put all that down and show the problems."

Armed with that information, doctors can more accurately adjust a patient's treatment and care plan.

Patients also can access CaringBridge, which provides a secure online connection where patients can find support. Games and a library app installed on the tablets give patients an outlet while waiting to see a doctor.

Rome News-Tribune

Our 170th year of service: 1843-2013

News Publishing Co., Rome, GA 30152-3533

B.H. Mooney III, President, News Publishing Co.

Otis M. Raybon Jr., Publisher

Pierre-René Noth, Editorial Writer

Compass to tomorrow

IT'S A BIG DEAL, as the news coverage elsewhere in today's paper about the launching in Greater Rome of MyJourney Compass, a national pilot project on the cutting edge of health-care provider interaction with patients, makes clear.

Perhaps one can call it a test of how medical "bedside manner" might evolve in the age of technology except that the target population (those with breast cancer) are largely ambulatory.

The impressive details of how this has been set up to work, and all the teamwork required to reach this stage, are spelled out on our front page today. While these make clear the importance of the innovation to those participating, there are far-greater implications hinting at benefits that may someday well reach all of us.

Additionally, here in a place where news of national or even international importance does not generally appear, it could be overlooked that this is something that might well have been near-impossible to launch in any location other than Greater Rome. In a way it is a tribute to this community's unofficial motto of "Working together works" as the team that put this all together made it quite clear that pulling it off might have been possible nowhere else — and not just because this is a community with a huge medical community.

WHILE THE RESULT may seem quite simple — a familiar haul-round computer tablet with special applications and data that patients can use to have questions reliably answered by experts, access all their medical information, test results and much more — what it really becomes is liberating to patients for whom the worry of being out of contact with their providers and trusted counselors when they have a question, a new symptom and so forth now often controls their lives. They are now free to move around the world while always being in the doctor's waiting room, so to speak.

And, addressing one of the growing worries of these always-connected times, all their information and communications are as private as Microsoft can possibly make it with HealthVault.

Yes, this is an "experiment," funded by the federal government's Office of the National Coordinator for Health Information Technology, and only one to two such being attempted nationally in the realm of improving information/contact between patients and those who care for them ... and to do it all the time.

It is not difficult to foresee the value this might ultimately have in improving outcomes — and peace of mind — not only for other cancers in the future but also all chronic diseases and conditions in which patients are not actually in a hospital but rather trying to maintain normal lives. Diabetics, heart patients and so forth could well, in a rapidly approaching day, be similarly served.

TO PUT IT into perhaps more familiar terms, this is the emergence of personal medical networking rather than social networking and could grow almost as rapidly, except this involves not just "chat" but instead meaningful conversation about real and deeply personal concerns. There will be no search-engine potluck but rather the most knowledge, information and advice available as rooted in specialized software programs designed for this specific effort.

The team members/components necessary to get this off the ground are many. The designers of MyJourney Compass were basically given all the many parts and components

necessary to invent a car and told to see if they could put one together. Each mechanic had special expertise, just as one doesn't have transmissions fixed by a brake guy.

They have built it and now it is being rolled out onto the test track.

Included in this team were Cancer Navigators, Georgia Tech, Microsoft, Google, the Northwest Georgia Regional Cancer Coalition, Harbin Clinic, Floyd Medical Center, Redmond Medical Center, the Greater Rome Chamber of Commerce, the Georgia Department of Community Health ... and others, all with roles to play and parts to bolt on to make a seemingly simple 7-inch android tablet dedicated to this purpose do everything demanded of it anywhere in the world that it might find the increasingly omnipresent wi-fi service.

While, it should be added, still being able to do everything else that consumers expect such devices to do, be able to slide them into a purse and not have to additionally haul around a notebook purposed for the other world of mobile doodads.

THAT IS NO small feat, particularly when keeping "your stuff" so securely private is required.

That Cancer Navigators was present to provide the human hub and instructional assistance was certainly a factor in this being started in Greater Rome.

Most residents probably assume, as they do regarding so much that is actually special and different about this community that every place has a similar organization. Wrong. Actually, many may even assume that every city this size or even larger has two hospitals, a major physician clinic, a stand-alone cancer center and so forth. The sad reality: Very few Americans have access right at hand to as much medical expertise as this region has built up.

One of the most-important things MyJourney Compass could wind up doing is making the whole nation, indeed perhaps the whole world, shrink down to the size of a Rome when it comes to having expertise and attending medical teams right at hand.

However, most of all and perhaps most important, Greater Rome may well be the only place around where pulling off this complex effort was possible because of its unique atmosphere of cooperation, its immersion in the thought that the late Napoleon Fielder is credited with originating during a more-divisive local era: Working together works.

As Gena Agnew, executive director of the NWGA Cancer Coalition headquartered in Rome, explained while noting that a spirit of teamwork was why this community was selected as where to build and launch this effort: "I have become so accustomed to everyone's cooperative attitudes that I am amazed when others talk about how hard it is for them to accomplish anything if partners have to work together."

NOR SHOULD it go unmentioned that Greater Rome's medical driving forces — Floyd, Redmond, Harbin and the rest — are known to be highly competitive for health-care dollars but also highly cooperative when the "bottom line" is better patient outcomes.

Healing together works, too. Perhaps MyJourney Compass will be the start of proving that, in a nation still somewhat confused about how to proceed regarding the many difficulties of health care, putting the patient first determines the best direction.

If so, it may well turn out that Greater Rome was where health care itself began to become cured.