INNOVATE

LEXINGTON INNOVATION STUDIOS

LAUNCH HOSTS EVENTS TO CO-DESIGN CANCER CARE

On October 7th and 8th, LAUNCH hosted two innovation studios at Markey Cancer Center in Lexington, Kentucky. The goal of the studios was to co-design with a diverse group of stakeholders better ways to monitor and manage cancer patient status throughout treatment. The October 7th studio focused on redesigning the currently used, paper-based monitoring tool, the NCCN "Distress Thermometer." The October 8th studio focused on creating an electronic version of both the NCCN and newly designed paper-based tools.

The new paper tool and the two new electronic tools were prototyped overnight by a remote team of designers. On October 9th and 10th,

Cont. p2

RAPID PROTOTYPING

WHILE WE SLEPT, P4

The advantage of having a coder in a European time zone became apparent when, seemingly by magic, our app was created while we slept, and ready for user testing the next day.

RESULTS

INTERPRETING FEEDBACK, P5

On October 9th and 10th it was "all hands on deck" as the LAUNCH team worked to collect user feedback on the tools developed just the previous days.

FIELD NOTES

HINDMAN, KNOTT COUNTY, P6

Chris Boyd, of the Appalachian Artisan Center, spoke with us about this organization's dual mission to promote the arts and fight the opioid crisis.

CO-DESIGN

worksheets, to ideate and design new ways to monitor patient status during cancer care. The activities were as follows:

Day 1
- Activity 1: Create categories and questions for a new monitoring tool
- Activity 2: Create other elements of the monitoring tool (scoring system, communication method)

Day 2
- Activity 1: Electronic app design
- Activity 2: Service design

Teams used cork boards and other materials to make a physical representations of the their ideas. Then, a representative from each team delivered a pitch to the larger group, recorded on video, describing the team's innovations.

Cont. from p1.

LAUNCH team members collected feedback on these new tools from providers attending the Markey Cancer Center Affiliate Network Annual Meeting, and from patients and caregivers present at the cancer center at the time.

FORMAT OF THE EVENTS

The innovation studios were organized and facilitated by **Melanie McComsey, Ming-Yuan Chih, John Kim,** and **Anna McCowan**. Participants were grouped into interdisciplinary teams of 3-4, consisting, ideally, of one LAUNCH team member, one patient or caregiver, and one healthcare provider. Lunch was served at the start of the events, and team members had a chance to get to know each other through icebreaker activities. Teams then participated in structured activities, guided by

OUTPUT OF THE EVENTS

The physical cork board displays, video-recorded pitches, studio photographs, and first-hand experiences of the LAUNCH team members were the immediate output of the events, which could be used by the design team to begin the prototyping process. The products of this prototyping process were projected to consist of a new paper-based tool to compare to the NCCN Distress Thermometer, and a new electronic tool to compare to the Digital Thermometer.

COMMUNITY-BASED INSPIRATION

The idea to co-design a new form of electronic distress monitoring along with its associated services model came out of a previous LAUNCH innovation studio held in McKee, Kentucky, in June 2019. At that

event, residents of Jackson County, a rural, eastern Kentucky county, pitched ideas for anything they thought could help local cancer patients. Two of those ideas stood out for their similarity and practicality:

- A device and application that allows patients to text message their providers with questions;
- A way to loop together communication between the

patient, a patient navigator, the primary care provider, and the specialty care team, possibly through a device or app that matches patient needs with the right person.

These ideas from the McKee innovation studio inspired us to develop a new, connected system for patients to communicate with their providers during cancer treatment.

TEAMS PITCH IDEAS

Pitches were video-recorded and posted online so that anyone can build, test, or sponsor one of these ideas. Watch the video pitches at launchhealth.org/pitches.

In the first set of pitches, participants described their ideas for improving the content, questions, and wording of the monitoring tool. Here is what they said:

1. You and Your Stress Scale: This scale is the 'you and your stress scale.' It doesn't have 'cancer' in it because some patients take this before they have their cancer diagnosis. We want to know about your stress. We want to help the care team know

how your condition affects your life.

2. Wellbeing Thermometer: It's a simple, context-driven assessment tool.

3. My Cancer Path: A dynamic tool reported at the frequency of patients' needs that uses patient reported outcomes and trends to indicate the urgency of response.

4. Total Wellness Scale: It's a total gauge of wellness because we know that one thing in your body can affect others.

5. Communication Link Between Patients and Providers: You have a curated service network, you can click on it right away. But for providers, we love the idea that it's a case management tool.

In the second set of pitches, participants suggested ways to turn the survey into an app, and ways to design the accompanying services.

6. Prioritizing Areas of Need: In our app, we wanted to

enable the patient or the caregiver to prioritize their areas of need, and then to be able to tie that to the resources necessary to help them with that particular distress.

7. Integrating Into the UK Portal: Some of our key design features were integration into the UK portal. The reason for this is that the patients were very familiar with the UK portal and also the lack of passwords; because of 'chemo brain,' they tend to forget things.

8. Access to Care at All Times: One thing we wanted was a button, right away, before you log in, to address any urgent issues.

9. A Dashboard to Give Patients a Choice: It empowers patients to advocate for themselves by selecting what symptoms they want to address, how much they'd like to share, and choosing what categories are more important to them at the moment.

POST-STUDIO WORKSHOPS
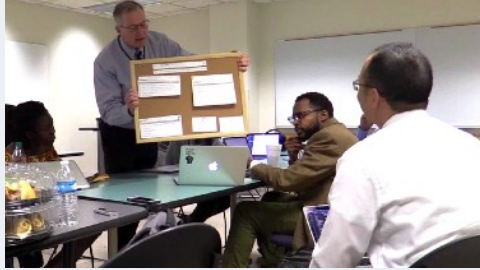
After each innovation studio, LAUNCH team members convened to process data and to narrow ideas based on frequency, feasibility, and effectiveness. Each LAUNCH team member described the ideas and processes of the group they had joined for the day. These post-studio workshops were attended via video conference by our remote design team. Above, **Tim Mullet** explained his group's designs to the remote team on the computer .

CAPTURING THE MOMENT

Documentation was key to communicating the output of the innovation studios to our remote design team. UK students **Melissa Martinez** and **Kelli Burnett** took photographs during the events. Idea boards were carefully documented. Videos and transcripts of the pitches were shared online.

PROTOTYPING WHILE WE SLEPT

Following the first innovation studio and post-studio workshop on October 7th, our remote design team got to work creating a new, paper-based patient monitoring tool. **Pia Nyakairu**, a human factors designer based in Toronto, and **Eli Aronoff-Spencer** in San Diego, spearheaded this effort. By the next morning, the new tool was ready to be

even more work to do. This time, our expert coder **Didi Hoffman**, based in Berlin, took the lead. As we were winding down to rest after a long day, Didi's day was just beginning. He worked while we slept to create an electronic tool based on the language of the "You and your well-being" survey and on the output of the October 8th innovation
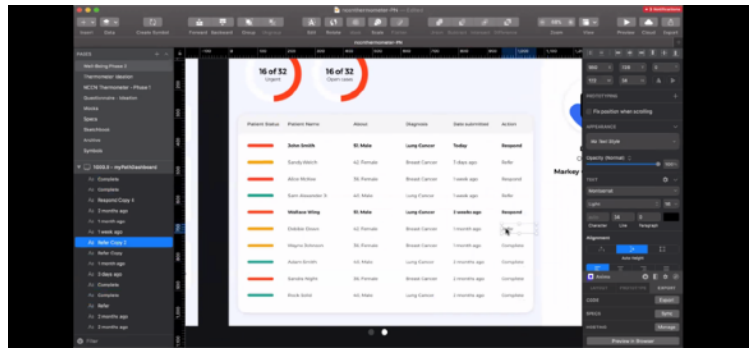
A screen shot of Eli and Pia collaborating via Zoom on a prototype of the MyPath provider dashboard.

printed and used as inspiration during that day's innovation studio.

The new paper-based tool, dubbed "You and your well-being" by participants, differed from the NCCN Distress Thermometer in organization, language choice, the use of scaled rather than binary responses, the addition of several validated mental health questions, the addition of open-ended questions, and aesthetics.

The next day, following the innovation studio and post-studio workshop on October 8th, the design team had

studio. This app was originally called "My Cancer Path," later shortened to "MyPath."

Prior to the innovation studios, the design team had created a prototype of a "Digital Thermometer," an electronic app analogous to the NCCN Distress Thermometer. The Digital Thermometer preserved the language and imagery of the original tool. As we move into testing phases, users will be able to compare the Digital Thermometer and MyPath apps. Both are available at https://distress-thermometer.netlify.com.

COLLECTING USER FEEDBACK

On October 9th and 10th it was "all hands on deck" as the LAUNCH team worked to collect user feedback on the tools developed just the previous days. One contingent, including **Alyssa Donawa, Esther Max-Onakpoya, Anna McCowan,** and **Ming-Yuan Chih,** set up a booth in the lobby of Markey Cancer Center to collect feedback from passersby, including patients, caregivers, and providers.
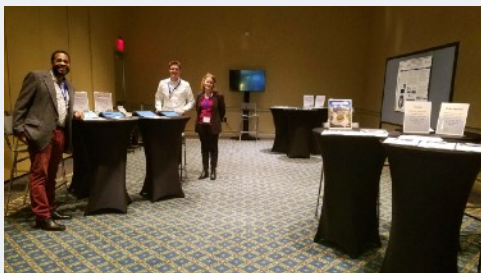
Another group, including **Victoria Atencio, Corey Baker, Meghan Johnson, John Kim,** and **Grant Patterson**, hosted a showcase at the Markey Cancer Center Affiliate Network Annual Meeting at the Lexington Convention Center. The meeting is attended by cancer providers and researchers from across Kentucky, and provided an excellent venue to collect feedback from a knowledgeable pool of attendees. Special thanks to **Tim Mullett**, who provided access to the event.

PRELIMINARY RESULTS FROM USER FEEDBACK

On October 9th and 10th, both at Markey Cancer Center and at the MCCAN Annual Meeting, LAUNCH personnel collected feedback on the tools co-designed during the innovation studios. Participants were asked to compare *either* the paper NCCN Distress Thermometer to the co-designed, paper-based, Well-Being Survey; *or* an electronic app based exactly on the NCCN Distress Thermometer to the co-designed MyPath electronic app. Participants had access to the two tools they would compare, and filled out a paper survey including demographic questions and the 10 questions from the Standard Usability Survey (SUS).
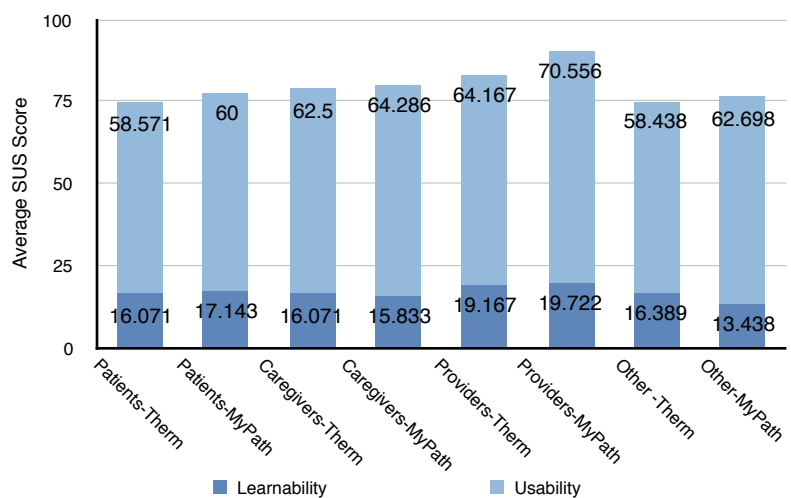
We collected 46 surveys assessing the two paper-based cancer symptom monitoring instruments.

Cont. p.7

Comparison of paper tools: Old (NCCN Thermometer) vs. New (Well-Being)
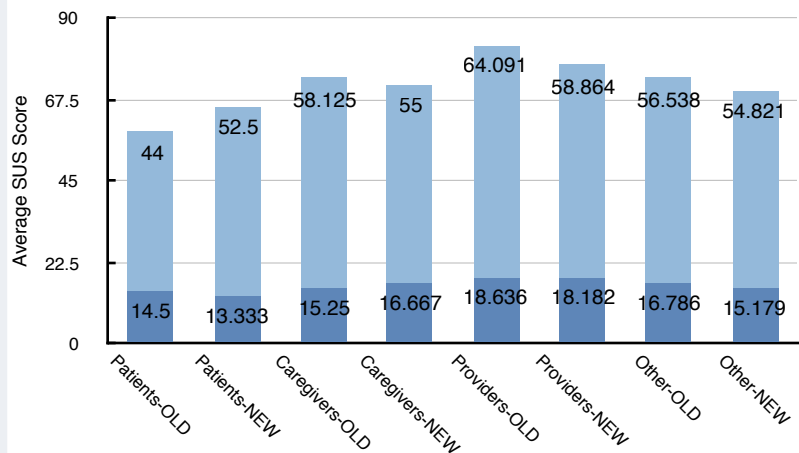
Comparison of apps: Digital Thermometer vs. MyPath App

■ Learnability   ■ Usability

A MODEL FOR COMMUNITY-BASED INNOVATION IN HINDMAN, KY

Chris Boyd, *Director of Fundraising and Development at the Appalachian Artisan Center in Hindman, KY, spoke with us about this unique organization's dual mission to promote the arts and fight the opioid crisis. An excerpt from her interview appears below.*

"   So the Appalachian Artisan Center was created in 1999. I think our doors opened in 2001. It was created with the money from a DLG grant and it was to take, I guess, up and coming artists in Appalachia to a different level, not just craft shows and that type of environment, but showing that they could be artists as a profession. I started sitting on the board in December of 2013 and then I became the fund raising director, development director in the summer of 2017.

"One of the things, especially at the Appalachian Artisan Center and even the Hindman Settlement school, we work at putting artists in schools because K through eight, there's no art teachers in this county. Budget cuts are one reason. Another, people aren't studying art. So we do that. Then the high school recently got an amazing art teacher who has been working with us, and what we've done is we have murals that we painted that are part of a walking trail that was created for health conscious people, whether it's the diabetes foundation, farmer's market or just people in the community. We have got money from the NEA where we have public art. We feel like art is the part that gets people out and about. We have an art show that's related to our festival, our little gingerbread festival, that's all the kids in the county, the schools, because it's important, art has to have a presence from a young age… Then one of the biggest things that I like community wise is the exhibits that we do of our artists. I call this place the MoMA of Appalachia.

"Our former executive director wrote a grant called the Culture of Recovery, and that program was to help fight the ongoing opioid epidemic that is just

ravaging, not just Eastern Kentucky, but from here to Florida and Pennsylvania and West Virginia. It was to give a different perspective in … It wasn't art therapy. We didn't want to do that because there's so much more to that. We wanted to teach them something that would make them proud of themselves, to give them a sense of accomplishment. So we had the pottery studio, we had the luthiery and blacksmithing, and we worked with the drug court, which was in Magoffin County, and Hickory Hill Rehabilitation Center, which is an all male facility here in Knott County. What has happened out of that, the success stories have been great.

"Of course, that grant really put us, people realized we were doing more than just selling art or doing art. I think that's kind of how it came about. I don't say I a lot, but my big story is I left here when I was 18 and my last words to my grandmother was, "I am getting out of this godforsaken hell hole." Those were the exact words. When I was 30, I was living in New Orleans and I was getting divorced. So what do you do? You come home because we take care of our own.

Cont. p7.

Cont. from p6, Hindman

"I came back and all the things that I didn't want when I was 18, it was small, people knew what you were doing, turned into being such a–It filled a void that you have when you're separate from it. It's like anything about Appalachia, you don't necessarily know you miss it until you're not in it. Then you come back and you're like, 'Oh, I love Sunday suppers after church.' I love being able to stop at the IGA and three people you knew growing up, they either work there or they're shopping there, and you're connected. Everyone's connected, and in a world like we have right now where even though technology connects us all, we are truly disconnected, and so you have to fight, I think, to keep that small town community feel. And that's kind of the way everybody sees it, I think, here, now. I'm not the only person, although I say this is my penance, was to come back and do everything I could because I didn't appreciate it the first time around.

Cont. from p5, User Feedback

The median age of survey participants was "over 50." More than 90% used a smartphone. Three participants reported not having a smartphone: 2 patients and 1 caregiver. Among the 43 smartphone users, 33 (82%) had iPhones and 10 (22%) had Androids.

We collected 34 surveys assessing the two electronic cancer symptom monitoring instruments. The median age of the 34 participants was "over 50." More than 90% used a smartphone. Two participants reported not having a smartphone. Among smartphone users, 27 (79.4%) had iPhones and 7 (20.6%) had Androids.

Overall, the key findings were as follows (See Figures on p5):

- Patients preferred the co-designed paper and electronic surveys to the Thermometer versions.
- Providers preferred the NCCN paper tool, but the MyPath electronic tool.
- All users preferred electronic tools to paper tools.

INNOVATE