Catalyzing Computing Episode 33 - Health Informatics with Katie Siek (Part 1)

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[Intro - 0:00]

Khari: Hello, I'm your host, Khari Douglas, and welcome to Catalyzing Computing, the official podcast of the Computing Community Consortium. The Computing Community Consortium, or CCC for short, is a programmatic committee of the Computing Research Association. The mission of the CCC is to catalyze the computing research community and enable the pursuit of innovative, high-impact research.

In this episode, I interview Dr. Katie Siek, a CCC Council Member and a professor in Informatics and the Chair of Informatics at Indiana University – Bloomington. Dr. Siek is interested in integrating pervasive technologies in health and wellness environments to study how technology affects interventions. Her research interests include human computer interaction, ubiquitous computing, and health informatics. In this episode Katie discusses health informatics, fitness trackers, data ownership, and aging in place. Enjoy.

[What is Informatics - 0:55]

Khari: So you're listening to the Catalyzing Computing podcast here with Katie Siek, professor in Informatics and the Chair of Informatics at Indiana University – Bloomington. How are you doing today?

Katie: Doing good. How are you doing?

Khari: I'm doing well. So where did you grow up and how did you first get involved with computer science?

Katie: I grew up on Long Island, New York. I'm a first generation college student. When I was in elementary school I wanted to learn to play the piano, but my dad went out and he bought an [Atari 800](#) instead.

[Laughter]

But he told me that it's not a big deal, he would teach me how to program it using a language called [BASIC](#). My dad did not go to college. He worked in the county parks department maintaining the parks, and he taught himself BASIC in the evenings, then taught me how to make every key make a sound. And that was kind of it — I was totally hooked.

I was like, "Oh my goodness, I can control something in my life. I can control this computer." I still didn't really understand programming, but I knew enough to copy and paste examples and get it running and see what it did.

Khari: Cool. So what is informatics? What kind of problems do you study?

Katie: Yeah, that's a great question, especially because in Europe informatics is kind of thought of as computer science, but here in the United States we have computer science and then we also have informatics. The way we define it is, it's where people and computing come together. So we look at ways we can practically apply computing to solve real world problems.

Some examples: I work in the intersection of health and wellness and computing, so I look at, is there a scope of technology that can help solve some of these problems? And if so, how can we do it? I've worked with people who have end-stage renal disease, who have low literacy, and I looked at how we can design dietary management apps for them. All the way to low-income families who are trying to deal with lots of societal issues but also trying to control their family's nutritional needs and how we can help them with that.

There's other parts of informatics. There's music informatics, there is bioinformatics, and security informatics. Basically any real-world problem you can apply computing to.

Khari: Ok, so your work is very...I guess, hands-on isn't the right term, but interacting with people a lot.

Katie: Yes, my whole day is interacting with people. I especially like working with community members and really making sure I'm talking with all of the target users of a system.

Khari: So what are the big challenges to doing informatics research, especially if you're dealing with all kinds of different groups of people?

Katie: Right. Well, from a technology standpoint, I think the the biggest challenge for us is the data we're using, in terms of how accurate it is, how we can process the data without bias — especially since we are working with diverse groups — and then how we can visualize all the data we're collecting and making actionable for people, because we're working with people of different cultural backgrounds and literacy and numeracy understanding. So it's fairly challenging and in fun settings.

In terms of working with people, I think there's two big challenges. One is making sure that we are addressing a problem that they care about. There's the research problem and then the problems that they have, and we have to kind of come together. And the other part is to keep those relationships strong and to have a continued presence. Instead of just coming in whenever you have a study and then leaving, you have to be there continuously. You can't just get up and leave when you're done collecting data for the day.

Khari: Right. You mentioned the need to make sure you're addressing the problems people in the community have. So, for your projects, what is one of the ways to figure out what people want? Like, how are you approaching that?

Katie: Yeah, it takes a lot of time. Things that we typically do are: we try to find a nonprofit or a community center that we can work with. Then we go and we visit them, we talk to them about their interests, and we find out what they need. This is also kind of where funding comes into play. I have to see what they need.

One time we had people who said, "You know, we really need computers, we need laptops for our after school program."

Great! That's definitely within the scope of my research. I can say, "We're going to also use these systems for various studies," and so we can get you laptops for your community.

Others were saying, "Oh, we really need a dietitian or a nutritionist in our community center to help with families."

And I said, "Great, that nutritionists will be our expert person who will help us make sure our apps are accurate." So then we were able to partially fund someone there. So that was our continued presence in the group and they understood they were part of our research team, too.

So, part of it is understanding what they need. The other part is understanding that the problems we want to address have mutual benefits. We come in and ask them, "What are the big problems?" We typically have multiple meetings, especially with community leaders. We have to work hard to identify community leaders. Then we have larger focus group meetings. A lot of times I'm just paying out of pocket, hosting dinners in communities, bringing in Subway or whatever food I can bring in to have them come in the evening and talk to us about like, "This is what we hear, is this what you're experiencing?" and get their feedback.

Then as we're doing the studies, we typically volunteer in the community. Like volunteer for homework support. I've done cooking workshops. This is in addition to the computing research. Then we're actually doing our studies. We typically have periodic, almost quarterly community meetings where we're showing our results, getting feedback, hearing about what their interests are.

Khari: So, you said you do things like cooking workshops. Is that just to build a sense of community or are you using that to study, say, people's nutrition?

Katie: A little bit of both. It was actually pretty eye opening when I did a cooking workshop. We were working in a lower socioeconomic status population in a public housing community. I did the workshop in one of the homes and there were people from the community there. I was like, "Yeah, I'm going to work in this kitchen," that I was not used to working in.

First, trying to teach cooking in a kitchen you've never worked in before is a challenge. And then, you know, I was trying to show how we could cook...My lab also did a challenge to say, "Ok, this is the typical income for a family of four. This is how much they would get with the various benefits they receive." So trying to cook for a family of

four for a week in one of these kitchens, showing them how it's possible. I had also practiced multiple times. My family was getting tired of eating the same meals for a week.

[Laughter]

So I was practicing and I was like, "It's got to be good, I can do this." Then to go in and actually cook it in this smaller kitchen with less resources, I was like, "Oh, this is challenging."

So it made me more empathetic to the people that we were working with, and they also got to just know me. As you're cooking, it's one of those communal things where you talk about other issues while you're waiting for something to bake. I had all my kids there and they had all their kids there. It was a fun challenge.

I came out of that thinking, "People need more resources. Families need more resources. If our app is going to recommend baking, we've got to make sure they have baking pans." All these little things that you take for granted.

[Fitness Trackers and The Accuracy of Their Data - 9:20]

Khari: Yeah, that makes a lot of sense. So you mentioned one of the challenges is having accurate data. You wrote an article for *The Conversation* — I guess this came out about a year ago — about fitness trackers and why they might not be accurate. So can you kind of summarize that article and those challenges?

Katie: Right. So this article came about in two large-scale studies that we're doing. One is, I'm part of IU's (Indiana University - Bloomington) precision medicine initiative where we're specifically looking at how we can predict women who are at risk for gestational diabetes. Typically women with gestational diabetes are also highly likely to go on to develop type 2 diabetes, so in this project we're looking at everything. I'm collaborating with a lot of colleagues.

My part of it is to look at their fitness. We have them wearing a Garmin wearable. We recruit three months before they give birth, all through birth, and then a couple of years after birth. So we have hundreds of women wearing these wearables for at least two and a half years.

Khari: Wow.

Katie: And then another project I'm working on is with older adults. It's funded through the National Science Foundation (NSF) with some colleagues here and at the University of Missouri and Clemson and Penn. There we have smart sensors throughout homes. And my part, again, is looking at how older adults are doing fitness outside of their home. They have a different Garmin wearable that they're using outside their home.

But in both groups, what we kept hearing in interviews with them is they're saying, "You know, I think I'm walking a whole lot more than what I'm getting credit for."

[Laughter]

And sure enough, when we were looking at their data, especially in the smart home situation where we could sense how much they're walking within the home, the data was not quite adding up. One of the things is that, for the accuracy in this article in *The Conversation*, the wearable that you have has something called an XYZ accelerometer. And it's basically looking at how much you shake your arms as you move. So if you're not walking with the standard gait, then you are not going to get the steps. And the algorithm is their own intellectual property, so they're not going to share that algorithm with everyone and tell you, "This is exactly how we're doing it."

This is my take with older adults: that they are shuffling or using a walker or using a cane. They're not going to be moving their arms as much. Likewise, when women were pregnant and as they continued on with their pregnancy their gait changed because they're adapting to the changes in their body. I had a similar experience with this where I pushed my stroller and my wrist wouldn't move and I wouldn't get the credit for it. So, yeah, there's a lot of accuracy kind of issues with this.

Khari: Hmm. In the prep work for this, you mentioned something called an [actigraph](#). What is that and how does the accuracy of that compare to most wearables?

Katie: Right. An actigraph, especially in public health studies, is kind of like the top-of-the-line, medical grade wearable that is known for being super accurate, especially with your step counts. This is when we're comparing commodity wearables like Garmin or Fitbits. Typically, they're also paired with an actigraph. So you can kind of compare them and see the accuracy. Research has shown that for sedentary behavior commodity wearables are great, especially with kids and older adults, and sometimes with light exercise. But the performance kind of tapers off once you get into more physical exercises or various activities.

Khari: Is the actigraph a type of wearable or is it a model of building it?

Katie: It's a type of wearable. You can buy it online. They're trying to make them better looking. Initially, just a few years ago, the actigraph was basically just a black box you wore on your wrist; it didn't give you any feedback. You would get the feedback when you sync with the app or with the researcher or whatnot. But now they are making them a little bit more feedback-to-people, especially since people are requiring it. Like the commodities lead the market in terms of what they what people expect from the wearables.

One of the things with the actigraph, like why don't we use actigraph all the time is that they are really expensive since there are better sensors. There's better algorithms and software in there that can detect walking and various activities. So they're kind of not the same price as your typical commodity wearable.

Khari: Hmm. So how much is a typical commodity wearable? I don't own like a Fitbit or anything. And how does it compare to an actigraph?

Katie: Yeah, that is an excellent question.

[Laughter]

Katie: So a Fitbit or a commodity wearable, again, it depends on how good you want. You can probably get one for, you know, $30, $40, $50, especially when the sales are happening and then it just increases from there. One of the things that makes commodity wearables a little bit...well quite a bit more accurate is that they also have GPS in them — but GPS is pretty power hungry. You can't always have GPS on all the time. It would be really nice, and I've had some undergraduate researchers playing around with apps that we can design for the system that can kind of ping GPS periodically so we can get a better sense, but even that is pretty tough on a battery.

And, you know, users don't want to necessarily charge something every day, especially on their watch. They're already charging lots of different technologies, maybe a phone, maybe a tablet. They don't want to maintain their watch as much.

[Laughter]

Whereas an actigraph can be a couple of thousand dollars. So, you have something that's fairly cheap versus something that is pretty expensive.

Khari: Right. Ok, yeah, that makes a lot of sense. So, have you found that the lack of accuracy causes users to stop trusting or using their devices in any of these studies you've done?

Katie: Yes, absolutely. I find people kind of go two ways. The first stage is they get frustrated with the device — like they know they didn't have a great night of sleep or they know that they really did walk. They know that their block is a half mile, so they get frustrated with it. But some people, that frustration will drive them to kind of give up on the device, whereas other users will actually adapt to get credit.

And my work here also reflects other studies. Like people have said, "Oh, I stopped biking because I only get credit when I run." So they'll look to get credit and we have seen some adaptations. Some commodity wearables do sense when you're biking, do sense when you're swimming. So they are working on it, but, again, there's always that accuracy frustration, especially if you are running on a track or you're swimming in a pool. You know it's not quite working properly.

Then some users are just ok. They know it's a rough estimate and that's ok to them. So it kind of spans there.

[Data Ownership - 17:16]

Khari: Ok. So what are the current issues with data ownership when it comes to these sort of wearable devices? Where does that data go and who has access to it?

Katie: So one of the things with data ownership is that...I have at least two studies going on right now with Garmin wearables and I never get the raw data. I only get the abstracted data that their algorithms have told us, like, "Oh, this is what we estimate for their walking." You don't get to make your own algorithm here, and that's a frustrating part, especially when we're working with specific populations like pregnant women or older adults, I [want to be able to] say, "This is their gait. Now, I want this to be a step," but I don't get to make that choice.

The other concern as a researcher is, in computing we have garbage in, garbage out — if our algorithm is trying to assess who's at risk for gestational diabetes and then we're like, "Oh, people who walk this much are at risk," but that data is not accurate, then the whole thing can impact the entire trustworthiness of it. So that 's kind of one of the issues.

From a user point of view, in terms of "what's the problem here?", is that we don't quite understand who has our data and what are the implications of that. When we talk to participants, a lot of them will say, "Well, I own my data. Here it is. I can see it on my app. This is my data," without understanding the user agreements that said," Oh, you know, this group has your data."

Then, maybe you used another third party app — like I use [Strava](#) because I like to social network and show how much I'm running with my friends — so then you've just brought your data over to Strava, and maybe every time there's an advertisement or there's another competition or app you're sharing your data again. You don't really understand how far your data is being shared.

And our data does have value. You know, things can be marketed to me. It can maybe affect my insurance. There's lots of little things that can possibly be implicated here, but no one's quite looking into how we can manage it.

Khari: Yeah, the CCC and CRA recently released a series of [quadrennial white papers](#), which explore topics around computing research with the potential to address national priorities. You can find those on the white paper section of the CCC website, which is [cra.org/ccc](#). One of those white papers is related to data ownership. It's titled [*Modernizing Data Control: Making Personal Digital Data Mutually Beneficial for Citizens and Industry*](#). You are a co-author on that paper. Could you discuss any key takeaways or things you think people should know?

Katie: Yeah, so something that came about as we were working on this...and it was great to be with a group of colleagues from all different disciplines thinking about this…[The white paper] gave examples of unintended consequences. So I just kind of think, "Oh, my Fitbit data or my Garmin data can maybe get seen by my insurance company and they can decide Katie didn't do a great job exercising in her 40s, so we're not gonna…"

[Laughter]

I mean, I'm just kind of thinking out loud here, but, you know, there could be those implications. But then they actually had real world examples where someone's pacemaker was used to show that someone did the crime. Like the police were able to get the pacemaker data. There's been issues where your own voice assistant has been being used in courts of law against the owner. The idea that you are smart devices could be used to prosecute you is quite an interesting piece.

The other thing that we've been discussing in this white paper is what do we do with this? Well, one of the things that really came about is that individually we have very little power to negotiate this and we don't have a whole lot of understanding. It would be kind of overwhelming if we kept getting pop-ups to say, you know, "Can CCC get your data? Can the insurance company?"

[Laughter]

You would just start saying, like, "yes" or "no" all the time and you wouldn't really have a rhyme or reason or understand what the implications are. The understanding, too, is that we have very little negotiation power. So we have to kind of think collectively. We have to come together as citizens and collectively negotiate our power with the industries. We have a few ideas of how we can do this.

Our white paper is more about letting people understand what are the implications, what we should be looking at, and what we have to start delving into more to ensure that citizens can actually control their data and know that it can't necessarily be used against them.

Khari: Yeah, so like I said, you can find that paper on the CCC website under white paper. The CCC website is cra.org/ccc. And the title of that paper is [_Modernizing Data Control: Making Personal Digital Data Mutually Beneficial for Citizens and Industry_](). **You can also find it on** [arXiv]().

[Aging in Place - 22:42]

Another project I know you're working on, you have an award from the National Science Foundation for [Toolkits for Aging in Place for Older Retirees]() **(TAIPOR). So what is aging in place?**

Katie: Right. So aging in place is typically this idea that older adults want to...you know, you've been in a community, you want to stay part of the community, and you want to be able to safely engage with it. So the idea is that you can continue living safely and with dignity in your own home or in the place that you see fit. Even if it's a different community, you can live there.

The other thing I recently learned about — in my head I always thought when I get older I would go to an older adult community and that's how it would work, but I've actually learned about how expensive this is and how a large part of our population does not have the resources necessary to do this. Living in your home is kind of the cheapest

way to go. So there's the idea of, like, we want you to live in place safely and with dignity, and the other part is that, like, maybe you can't live elsewhere, so how do we help facilitate that?

Khari: Ok. What kind of technologies are needed for aging in place? What have you been working on?

Katie: Research in aging has been going on for decades and what I really enjoy seeing is how the research community has kind of matured in our understanding of this, because early on we were saying, "Oh, we need to work with older adults and we will go to experts in older adult caregivers." So in a lot of that research we actually weren't talking to older adults, it was more about the caregivers and gerontologists and such. It was very much about monitoring people in their home as if people weren't going to go outside their home. A lot of it was about safety, like, "did Mom fall today? Did Dad have any visitors today? Is there anything I have to worry about?" It was very much in the home environment, but then we started looking at these sensors and we started talking to older adults about what they actually want. And the sensors got smaller so we can put them on the body and people can travel in their community. Now I think we're almost in this third wave to say, "Right. With smart cities and such, like you can be all around your community and aging in place."

So what is aging in place technology? It could be everything from your voice assistant, like your Alexa, to the wearable that you're wearing to see how much you're walking or who you're talking with, all the way to those standard sensors in the home to make sure you haven't fallen and you can get help, to your city — there's a great project at the University of Michigan using wearables to kind of see if the city infrastructure itself is safe for older adults. Do we need curb cuts? Is someone stumbling here? So aging in place technology now is broadening and expanding to also commodity technology and special case technology.

Khari: Ok. So do you think there are any risks to relying on, sort of, offshoring the physical and emotional caretaking of older adults to machines? We already kind of talked about data inaccuracies and data ownership, but maybe there's also online misinformation if these systems are connected to the Internet. And user error is always a possibility.

Katie: Yeah, there's a lot of risk to offshoring these systems. One of the things that I think about often and I talk about a little bit in my work is the scope of technology. Should the technology even be here? Is it something that a human could do better? I think caregiving is one of those things where I don't necessarily want someone to be

isolated, especially social isolation, especially in the time that we're living in now with COVID-19, right?

One of our projects that we're working on through TAIPOR is allowing older adults to create these check-in systems. So I have a check-in system and you have a check-in system — it's very much for rural adults. In past work, my colleague [Kay Connelly](#) found that in urban areas people would sit on their porch, sit on their stoop, and just wave to people. I knew that you were ok because I saw you walk by today and you always walk by at this time. But in rural communities you can't really do that. We're a mile or two away from each other, it doesn't work. So we create these check-in systems with the TAIPOR toolkit so that I can wake up and push my button and it would light up. Likewise, you push your button and it would light up.

I can use this in two ways. One, I can be like, "Oh, he's up so I can give him a call." Or you can say, "Oh Katie didn't check in. I better give her a call and make sure she's ok." One of the things that we're testing here is to make sure that it doesn't lead to isolation. Just because you see my light on you're not like, "Oh, she's good. I don't need to call her." We want to make sure that doesn't happen.

The other piece about offshoring caregiving to technology is actually understanding people's true physical needs. And this is super cultural, it's super personal. A typical example: I was talking with a caregiver that said, "If you asked my dad how he's doing, he's going to say he's fine."

And in technology, we would often be polite and ask, "How are you doing?" Or, you know, give us some input.

"But," she said, "If you really want to know how my dad's doing, you should ask him if you went to the bookie today."

[Laughter]

"And if he didn't go into the bookie, then something's wrong. He either didn't want to walk or something's hurting him." And so that was actually her little signal of how her dad was doing. In these systems...if we're designing these big systems in mass without this personalization, I wouldn't know what is the true question to see how you're doing, to make sure you're walking and talking to people. So how do we figure out that information? I think that's more of a personal person requirement.

Khari: Yeah, I guess on a practical level, how would you do that? Like, let's say you have a system that helps you check in with your kids so they know you're ok. How would you make it be targeted in such a way, as opposed to just, like, asking if they're fine?

Katie: So I think with these kinds of things, it would be something where there would have to be either some interview or some questionnaire with people to find out how do you really find out how your parents are doing? And it would have to be both ways. You would have to actually ask the older adult — and hopefully get the information truthfully — about who they would really disclose to if they were not doing well.

Because everybody in your social circle...like if I were to say to you, "How are you doing?" You're going to say, "Oh, I'm fine," because Katie's my colleague and that's our relationship, whereas if your best friend called you up, "You're like, let me tell you about my day."

So we have to kind of understand who in their social circle are the people they would disclose to; and then the other part we have to find out is how do they disclose this information, what medium, what questions. And then we would be able to kind of get that data. But still, if we created that system I really want to study, "what's the follow up?" Are you just saying great, push here if you feel better now or…

[Laughter]

I wouldn't want it to be marketed to be like, "Oh, they like chocolate. Click here to send them some chocolate." Like, I'd want there to be some physical connection or even social connection there. I don't want everything automated.

[Laughter]

Khari: So, related to this, I saw a paper you wrote, I think it was from 2005, called _Fat Finger Worries: How Older and Younger Users Physically Interact with PDAs_. You wrote this with Yvonne Rogers and Kay Connelly, and there was a quote that I thought was interesting. "This paper presents an initial usability study that shows there are no major differences in performance between older and younger users when physically interacting with PDAs and completing conventional (e.g., pressing buttons, using icons, recording messages) and non-commercial tasks (e.g. scanning barcodes).

So I found that maybe a little bit surprising, just because I would have assumed that older people would struggle a little bit more, just from a dexterity perspective, but that seems to not be the case. Can you talk about that paper or any newer studies related to that?

Katie: Yeah. What was interesting about that paper was we started that study because we were contacted by nurse researchers who were interested in creating systems for the low literacy population who had end-stage renal disease. We wanted to kind of make sure that they would be able to interact with the PDA, and quite a few of the participants were older so we did this older/younger kind of comparison. We were using an old, like, personal digital assistant (PDA). If you don't know what these are, they are pre-iPhone.

[Laughter]

They are a different type of technology, and the screen...it's not a glass screen. It's one of those where you actually have to push down and complete connection. So the technology was a whole lot different in this study. And yeah, I think part of it was that back in this time frame technology did have actual physical buttons, not just one button or no buttons. The buttons were fairly big on the Tungsten that we were using and [the participants] were able to interact with it. And then the screen, in terms of selecting it... they were able to select it, but again, this was actually holding a writing implement for this technology, so it wasn't using their actual fingers on it.

But there have been a lot of studies since and there's been like studies. Since technology has been changing so fast over time there's been some studies that [show] there's some touch screens that aren't necessarily as touch sensitive; because of changes in people's skin makeup it's not as resistant to touch. But the capacitive touch screens, they've been kind of revolutionized here. This is the newer technology that we have, and it's been really easy for people to, kind of, interact with it better.

I think one of the challenges, though, is they can physically interact with the physical system, but it's the design of the interface that can be more challenging. We did not necessarily do the design of the interface here. We do have other studies where we looked at how complex an interface could be and we basically found that once you go four or five screens in it's difficult, especially for older adults, to kind of navigate out. So you always need to have some kind of home button to get back to that original screen.

Khari: Ok. So by screens you mean like, I open my phone, I go into a text message, I click something in there. That would be two or three screens deep, I guess, and then….

Katie: Right. Yeah.

Khari: Ok. Interesting.

[Outro - 34:17]

That's it for this episode of the podcast. Tune in next week for part two of my interview with Dr. Seik. In that episode, Katie discusses health disparities and how computing technologies can play a role in the reduction. Until then, remember to like, subscribe, and rate us five stars wherever you get your podcast. Learn more about the work of the CCC on our website at [cra.org/ccc](cra.org/ccc), and find us on social media to stay up to date on our latest activities.

Until next time. Peace.