# Breast Cancer Awareness Month

October 13, 2023

**Becca Battisfore:**

Welcome to the latest edition of the College of American Pathologists. Cap caste. I'm back about is for content specialist with ACP. In this episode, Dr. Mary Edgerton will be talking with experts in breast cancer research, diagnosis and patient advocacy. One in eight women in the United States will be diagnosed with breast cancer in their lifetime. In 2023, the Susan G. Komen Foundation estimates that nearly 300,000 women and 2800 men will be diagnosed with breast cancer. Chances are, you know at least one person who has been personally affected by breast cancer. Advances in early detection and treatment methods have significantly increased breast cancer survival rates in recent years. When caught in its earliest localized stages, the five-year relative survival rate is 99%.

Today, there are more than 3.8 million breast cancer survivors in the United States. This month's Cancer Awareness podcast will explore what's on the horizon for breast cancer research, how it will impact patient outcomes and the role of pathology data in these efforts. We'll also welcome a patient advocate to share her experience and talk about the value of data to educate and empower patients as they navigate their cancer journey.

Before we get into the questions, let's have our guests introduce themselves. Dr. Edgerton, we'll start with you.

**Dr. Mary Edgerton:**

I am Dr. Mary Edgerton. I was at the MD Anderson Cancer Center for a long time as a breast pathologist, but now I'm at the University of Nebraska, and I also work with the CAP on the electronic Cancer Protocols.

**Dr. Regina Barzilay:**

Hi, my name is Regina Barzilay. I am a professor of electrical engineering and computer science at MIT. And I also lead the Jameel Clinic, which is Epicenter for AI and Health Care. My team and I do research on developing machine learning methods for clinical AI and for drug discovery.

**Dr. Ross Simpson:**

I'm Dr. Ross Simpson. I'm a pathologist, community pathologist at Methodist Hospital in Minneapolis, working with the Help Partner system. I deal with breast pathology every day. I'm also boarded in clinical informatics and work with the College of American Pathologists on the committee with cancer synaptics.

**Dr. Timothy Law:**

Morning. My name is Dr. Timothy Law. I'm currently working over at Phoenix, Arizona at Banner University Medical Center, which is actually the flagship hospital for University of Arizona. And last year I had the pleasure of working with Dr. Edgerton and all the M.D. Anderson's staff or M.D. Anderson Center as a breast fellow and happy to have to interact with you all today.

**Rebecca Seago-Coyle:**

So I am Rebecca Seago-Coyle. I'm a 13-year breast cancer survivor and patient advocate for Susan G. Komen and other nonprofits working to help patients.

**Dr. Mary Edgerton:**

Okay, Thank you so much. So, Dr. Barzilay, first, tell us, how does an engineer get interested in breast cancer?

**Dr. Regina Barzilay:**

So I personally don’t know any engineers in general who are interested in breast cancer. I can tell you about how I personally got interested in it. I got one when I was 43 years old. I went through the treatment at MGH and I was very surprised to discover how very little technology in AI is in this treatment. And I'm really glad that the American College of Pathology is interested and working on bringing this technology into the care, because up to this day, very little of the technology, almost ten years forward penetrated the regular treatment of breast cancer patients. And I really hope that we collectively continue it.

**Dr. Mary Edgerton:**

That's wonderful. So you say that AI has changed breast cancer treatment?

**Dr. Regina Barzilay:**

No, what I'm trying to say that AI there are lots of papers about AI and breast cancer treatment, but if you're looking at the journey as a regular patient and not only in the community center, but even in a research hospital like Dana-Farber, like MGH, like Sloan-Kettering, there is no benefit of AI today in treatment. If you're looking at the recommendations of the standard pathway for treatment, none of them rely on AI diagnostics on AI patient stratification. And this was the case when I was treated in 2014. Today, we’re in 2023 and unfortunately, this is still the case.

**Dr. Mary Edgerton:**

So what is the goal of your research?

**Dr. Regina Barzilay:**

So I look at various questions in AI related to breast cancer. So the first question that I was interested in and it's sort of related to my own diagnosis, but I discovered it later, is really correctly identifying the risk of the patients. Today, the patients, as we said in the introduction, one in eight women are going to be diagnosed with breast cancer, it is such a very significant amount. And it's, I think, the only cancer where we have federally regulated guidelines on how to predict risk, like, for instance, based on density, which is extremely, extremely noisy and inaccurate way to stratify women because, you know, close to 50% of women have dense breasts. So it doesn't really help to say to half of the female population that you are at risk.

So the first question we address is actually being able to look at the image which is currently considered to be benign when the patient still doesn't have any human identifiable sign of breast cancer and predict whether this patient will develop the disease within the next five years. So this is the first question that I'm trying to address and we were able to demonstrate and others replicated is if you actually can predict it, very reliably.

Other questions which are most related to pathology have to do with, you know, reading the pathology reports and identifying different features from the pathology report at least. The last time I checked in places like MASS Brigham General most of the reports are written in natural language and there is no effective way to look into these reports and extract patients with a particular characteristic. So we develop a system that can take this natural language report and translate it into a form of the structured forms that you can reliably query. So those are the things that they've done in the past. And if you're curious, they can tell you what I am looking at now.

**Dr. Mary Edgerton:**

Oh, yes, because as you may know, the CAP releases what they call the electronic Cancer Protocols. And these actually capture the data. They produce a little synoptic report and an executive summary for anybody taking care of the patient to look at and read with all the clinically actionable details. But then they extract this data into what we call an XML statement, and you can put it into a data repository and automatically query it. Have any of the organizations you work with started using this?

**Dr. Regina Barzilay:**

So in the past and I did look at this topic in the last year or two, in the past it wasn’t there and it's particularly important to look in the historic code of data when you want to see the projection of the patients. So the wealth of all the reports for the last decade or two that are stored in the MGB system, were not. They were just stored in natural language and of course you can query natural language, but there is no guarantee that you will find the right information.

**Dr. Mary Edgerton:**

That's true. And I just wonder, are the biopsies important to you as opposed to the resections?

**Dr. Regina Barzilay:**

So the way we've done it, so my work on the risk assessment was based on mammograms and MRIs. So didn't use the pathology data. With pathology, we used all the pathology reports on breast for variety of different reason, including for breast reduction surgeries and others to extract relevant information. So we were very general in the type of documents we could process.

**Dr. Mary Edgerton:**

Okay now you've given me an idea. I think we're going to have to have electronic cancer reporting for benign breast biopsies.

**Dr. Regina Barzilay:**

I think that actually it was very interesting because you can look sometimes like the data that we produced was used by various clinicians and researchers who want to look at the projections. So if you can look back, the patient is diagnosed and you have a full biopsy and the results, but you also can look back and extract all the other reports, not necessarily cancerous and then distend the trajectory of this patient's for whatever reason by a biopsy.

**Dr. Mary Edgerton:**

So I happened to have worked with someone we call the father of ductal carcinoma in situ. David Page, a very well-known pathologist. In fact, Dr. Law and I used to refer to him as Yoda Page, where Dr. Law was one of my trainees. Anyway, he actually kept a database and he insisted that when we read his consults and he collected slides into the database in data that we specify everything we saw benign and otherwise.

And then he would go back and search through his database to see if he could find any relationships. The database still exists at Vanderbilt. Very, very rich and really a great honor for me to honor. David Page during this this podcast. Well, imagine a world where you can get that data, where you can get that data from a synoptic report with disparitized data coming to you and you can build a repository and query it and have it all.

**Dr. Regina Barzilay:**

This would be really amazing, not only to me, but to many other institutions that are trying to get access to this data and really study the progression of these patients to understand what's going on. And I'm really surprised that- I'm now talking as a patient, not as a faculty, as a researcher- for instance, when I think about breast cancer and we're thinking about HER2 patients, we know that these patients recur later that it can be more than standard five-year period. Instead, it's 15. And so how come, and I'm one of those patients who takes Tamoxifen, who is treated and so on. But how come we still don't know which ones of these patients, looking at their biopsies, we cannot predict which one of the two were truly in the very high risk of recurrence when we're talking about positive patients.

So there is a lot a lot of information that is in this data is available and we can build the technologies that will give us the answer. But because we cannot resolve this problem of digital divide, where people will produce a data, have the data and people can process it typically sitting outside of the hospitals, because we cannot find a way to kind of put these forces together actually, the people who are paying the price are the patients. And this is, I think, very unfortunate.

**Dr. Mary Edgerton:**

That is so well put. And I'm hoping that all the pathologists listen to this. Take that to heart. I know we get, I would say, comments made about how complicated some of our Cancer Protocols are and some of them are. But I think that's a part of treatment in modern medicine is the more complicated our treatment is, the more complicated our reports are. And they're complicated because they need more information. And then again, there's the filling out forms and so on, so that this data can be collected properly and easily used.

I'm going to switch over to Dr. Simpson, and if I can call you Ross, I know you very well. How are you and how do you use the electronic report in your sign out?

**Dr. Ross Simpson:**

Yeah, I was just thinking about the story we just heard about how long it's come in my career. You know, when we started, we typed our reports and they weren't available electronically at all. They were just typed on paper and went up to the charts. And then we did go through the narrative phase when everything was narrative. And now, as you know, Mary, we use the synoptic reports and we use them. You know, they're required for the resections, and we're also using them in other ways. So we collect all of that data now histologic type size, everything else is discrete data, which is very useful down the line, but also useful to us. We do put one narrative line out. So in our standard workflow, we would put just invasive carcinoma.

No special type parentheses doctor, and then say, See Synoptic Report. So all of our data is in the discrete section. It avoids duplicate entry. I did work with the University of Mississippi, as you know, to work out a kind of narrative summary, extracting from the discrete data and putting that into a narrative appearing report at the top. And that way at least you still have one entry level. So we want to avoid double entry, which leads to sometimes erroneous results. When you were in difficult cases where you're trying to decide between two and you need to change it in two places, this just leads to errors. So we have done that. It's gone. It's gone. Well, we have now started using for the past year and a half, almost two years now, the breast biopsy templates, those are not required.

But we found when we looked at our data sets, obviously we had a number of cases in which they had complete response. And so with the resection, we had no tumor left. And so we really didn't have any data about that tumor in discrete format. We had a narrative breast biopsy report and then we had this resection report which had no tumor left. So we have done that now along with the biomarkers. So those are all available now discretely, and we're able to then now take all of our breast cancer cases from beginning to current time to and have them in discrete format and have a lot of data available to pass down best to pass down the line to our cancer registries or for our use.

So I know the next question is how do we use that data?? And locally we have a few goals. One of them is we did start looking over the data just to make sure we had some consistency. So we want to make sure that the report we're pulling has all the cases we expect. We want to make sure the data elements that we expect to be there are there, and we want to make sure there's consistency amongst our pathologists reading these. So occasionally get a new colleague in and may use the some of what they what we call the other category. And in the cabinets we have discrete data. But if you can't if you decide your answer doesn't belong, you put it in this other category. And we generally look at those other categories. And so we pull those out and we'll try to decide, is that something that we need to talk to a pathologist about and try to get them to use one of the more standard categories?

Because it met the 80% criteria for a special type or it didn't. The other thing we look at as we look at right into the CAP to we look at cases of where we think the template did not allow us to fill it out as we wanted to. And sometimes we go back to the CAP. And as you know, the CAP has a cancer committee that deals with these questions and will come back and tell us whether that they want to split that up and make that answer available or somehow or other otherwise change the checklist to make it amenable for use.

So then we went to where breast cancer group it. And we're local, we have a 3 to 400 bed hospital here. We have a fairly busy breast service. And we look really at the NCCN guidelines, but we still like to know what is our local data look like. So we started by pulling positive margins. So we went through our data set and as the positive margin is a discrete element. So we can say you show us all the resection specimens that had positive margins and then we look at see if there's variability on that by surgeon or by pathologist, by the PA. who did the gross by tumor size we looked at for quality.

You look at histologic types and we did find some variability. We're still in the stage now. We're trying to understand that variability. When pathology becomes a data model rather than just narrative, you have to think about things that we normally think about in laboratory medicine. So we look at statistics and what is our sample size and what is a variation, meaning what is the number. So if someone's surgeon’s result is a little bit different than million, it may not be statistically significant. So we try to bring those numbers into focus with regard to whether the expected findings are really different. We did look at histologic type. Most of us have biases. None of it's biases. But we certainly think that certain cases, for instance, I expected lobular cancer to have a higher positive margin rate.

And it did. It had a three times higher positive margin rate than the invasive doctors. The invasive ductals at our institution had a 5% positive margin rate and the invasive lobulars had 16% based on a sample size of about 600. So we'll continue to follow that data, but it's information that may not guide a patient's decision on what to do next. But certainly as part of discussion, I think it's nice to have an expectations and whether a patient expects to have a positive margin. And what are the chances of that? Our institution and have our data to look at compared to the global data? And I think when we look at globally, you look at the number of institutions now using the CAPs in EPIC, especially the large ones that will be able to compare our results to, you know, local large institutions in euros and figure out whether our results are different than others.

I think uniformity, when you're dealing with quality assurance the first thing is to try to get some uniformity. And I think the synoptics have helped that. We've basically- instead of a narrative report where people could write whatever type of breast cancer they want and use whatever terminology they wanted, we have unified that terminology. And people are now either stuck or forced or whatever you want to use. And some people don't like that. But the fact is this has language that we have to discuss with our colleagues and it has to have a common meaning and patients go to other places. And it's nice to have a common terminology at a discrete level to communicate our results and to compare them to other places and try to improve.

We have moved our biomarkers into the synaptic format with the with the exception of her two fish,. The HER2 FISH, we though we the made into a laboratory test. So it is discrete data. I think we could we obviously could do a 1 to 1 correlation so we could move it back into the CAP ECP terminology wanted because it's a 1 to 1 between the way we built it in the lab. But that that project did bring up another aspect that pathology and they need to look at. And then as we send off cases outside of our APLIS, how we link those back becomes critical to following the state. And for the researchers down the line to the line to follow this data so the researchers down the line need to know it is specific tumor has just had. I'm sorry, the researchers need to know if the specific tumor has a specific biomarker result. And in breast cancer, this can get complicated. We, at least once a quarter, get a breast with two different tumor types in a mastectomy specimen. And that's a case where you have to be very careful how you're linking these, especially on send up tests, both within our current allies are send out for like anchor type defects where they're going outside the institution.

And we find also, as we send the stuff outside the institution, a lot of that data gets in non desk. It's not discrete anymore. So that data comes back in either a narrative format, which we might have to do natural language search or as a PDF, almost like an image that you'd have to analyze. We'd prefer that stuff to come back as discrete data. And so far those projects have been slow and ponderous to try to get to try to get done. So I think pathology is kind of in an infancy with data science, with anatomic pathology. So I think we're in a learning phase and I'm excited about us making sure this data is accurate as it goes out and for the researchers down the line to be able to use this data.

**Dr. Mary Edgerton:**

I am excited about that. And actually, I think this information is interesting for patients. I mean, a woman might be making a decision between having breast conservation surgery and a mastectomy and if she has invasive lobular carcinoma, that may affect her decision. I also wonder if we could, and especially you, since you're using the biopsies, if we could use these to better understand which patients have a complete ecologic response because we go back to the biopsy and find out the histologic type and grade and and biomarker profile and then relate that to how many had complete pathologic response after neoadjuvant therapy.

And I'm sure that there are relationships to be discovered there. So I'm excited that your group is using the biopsies, I'm trying to talk my group into it and I think I had to be labeled as the person who drank the Kool-Aid. And I'm like, Well, I'm making it all for you all to join me. So I think that's wonderful. And I actually think that it can speed up your workflow because you're just selecting answers and moving on.

**Dr. Ross Simpson:**

The other thing I guess I want to say is that we're doing this here. I know other places have had more difficulty doing this, and I just wanted to say that is the CAP’s goal and we're working with the vendors and it's the vendors goal as well to try to make these kinds of reports easily accessible to the to the pathologists that you don't have to be an informatics pathologist to get this data. So the stuff we're talking about is coming to a lab near you soon, hopefully your lab in an easy digestible format that will not require an informatics degree to to do.

**Dr. Mary Edgerton:**

And that's a great segue way to Tim Law, who is new in practice. And Tim, I wouldn't have expected you to have a lot of experience with the data as Ross has had. He's actually led the effort in terms of their implementation of an APLIS. But how do you feel now listening to this about whether you would encourage the use of the protocols in in your practice?

**Dr. Timothy Law:**

Yeah, I mean, it was a very excellent discussion. You know, it's a lot of things I learned from Dr. Simpson this morning. You know, I think in my opinion we can use the tap synoptic, but also in conjunction with multiple different sets of data. I mean, we're using OP. I mean, we use Oncotype DX, we're sending off Oncotype DX, we're using Virtuso for IV C scoring, we're using Ventana for FISH. So somehow we have to incorporate the synoptic with all the different other information data set to create, you know, an expanded dataset that we could use, you know, breast breast pathology or breast cancer. It's that is truly multidisciplinary. So we really have to incorporate multiple different data sets, not just the synoptic, but that's going to be how many? I mean, just incorporating just synoptic, we're not even there yet. So I guess it takes multiple steps.

**Dr. Mary Edgerton:**

Right? Well, we have some exciting projects at CAP, but with some of our vendors we have what we call the Vinter Vendor implementation collaboration. And we go out to vendors and say, if we gave you a format and in an email to convert this data into where it could, you know, be divided so that the human reader gets the readable report and then the data repository gets the data to be linked to other reports on the patient and other data.

Really. And would you be willing to do that with us? And and so we're trying that with some of our molecular biomarkers. And I really see a great future. The other thing I've done is I've taken large language models, LLMs and ChatGPT, Bing chat, etc. and I've put in I had to teach it a little bit. You know, I put in the questions and I said and answer it with this answer, read this report I put in, made up a fake report, said, Read this report and answer these questions using this vocabulary. And I didn't allow any others. Yeah. And, and it generated a synoptic report for me. So could we actually combine and learn with a path list and have it generated synoptic report and generate the disk witness data in the background, then have that checked by the pathologists? I mean, to me, I hope I live long enough to see that.

**Dr. Timothy Law:**

I think you definitely will because I believe in all your I guess we have shared colleague Doctor Glassy. He gave a talk on chat about in our new practice meeting, and then he mentioned all the different possibilities you could, you know, you practice with a chatGPT. And yeah, you can just it can like analyze all, all the different ways that you have sign out cases in the past and then you just say certain keywords and just auto populate how you're signing up the case with the Synoptic Report. So yeah, I'm definitely seeing ChatGPT’s being utilized in so much outside of medicine now and seeing its performance so many different ways here.

**Dr. Mary Edgerton:**

Yeah that is something. So Ross...

**Dr. Regina Barzilay:**

Mary, I'm like listening to you and I'm concerned and to Timothy, and I’m like really concerned as a professor of computer science of the

**Dr. Timothy Law:**

The controversy of the ChatGPT is...

**Dr. Regina Barzilay:**

It's not a matter of controversy. First of all, it's important that people who actually are bringing this technology to a patient have a deep understanding of the technology itself and not just being a user. The second problem with ChatGPT is that we know the problem of hallucination is a real problem as it happens. And that again, and the quality of a generated text is so high that a human who is not paying very careful attention and it's not validating can be very easily convinced. So when we are talking about patient's life here and we're talking about doing research at scale on the patient's data, I think there should be many, many more check points. And really deeper conversation of how to introduce this technology so it doesn't introduce noise and distorts the results because the easily how it can theoretically can make things much easier for the provider, for the pathologist is very alluring to utilize the technology. But the consequences of it can be very, very serious. And as a patient and as a researcher who actually develops technology, it's kind of worrisome to hear this conversation.

**Dr. Mary Edgerton:**

Yeah, well, don't worry. It's not as though anybody has adopted it. I know that certain EHRs are talking about partnering with Microsoft to use it in their electronic health records. And I do want to add, when I say I had to train it, as I checked all the answers and I just made up a simple biopsy and my biopsy did not have any ductal carcinoma in situ in it, which was one of the questions, and I didn't see an answer. So it said, okay, ductal carcinoma in situ is present. So I had to train it to say, if you don't see an answer, then don't include that data point in there. Don't include that question, don't make up an answer. Yes, it does hallucinate. And actually the the usage that I'm talking about here is really very, very simple.

It's really almost in NLP, except don't make up answers when you don't see it. But I agree with you. I have a friend who's a computer scientist and and he went through a long chat GPT and, and they do have a very good vocabulary and their responses sound very real and then what was interesting too it's is or his lab I don't know which one it was is LLM would apologize when he would tell them Oh you're wrong. It would apologize but then it would go on and expound again. And he was not really understanding the geography in terms of the question it was being asked.

**Dr. Regina Barzilay:**

I think that the point and it's important question that the American College of Pathologists should be thinking about what are the applications where one has a high tolerance to error and it's not going to have any negative feedback is what you've done was a very correct thing you double check with. I mentioned to yourself that you are using technology every day. If you need to double check every single unsaved cluster for yourself to go and just do it directly. So we are talking about this reliance on the technology and there were a lot of studies on other uses of AI when the doctor uses it because they trusted the checked once and it was good and then they stopped paying attention when the things are wrong. So this is a good question for the FDA and others which uses can really be integrated to help make your life easier and which uses really have to be significantly more tested and further developed and utilize until they can really be part of the pipeline of a clinical pipeline.

**Dr. Mary Edgerton:**

That's absolutely correct. You do you do get accustomed to reading through a synoptic or let's say I have something transcribed by someone, but there are so many times where my eyes just glaze over and say, Yeah, yeah, yeah, yeah, yeah, yeah, yeah, yeah. That's what I said. That's what I said. That's what I said. Okay, done. Oops. Nope, that was not correct. So it is a challenge and I think I'm a pretty careful pathologist. It is a challenge to introduce a tool that will help you to ease your burden of work, but to make sure that that you're checking it. Ross, you wanted to add something?

**Dr. Ross Simpson:**

Yeah, I think, you know, I think I see it more as I'm excited about it more as an assistive technology. You know, even in our data sets we have now, we have cases in which you have a low-grade breast cancer event. It comes out ER negative. That's the kind of thing that should, I could certainly come up with and say, hey, this is an unusual situation. There's these other things that look like low grade breast cancer that are ER negative that you should consider to really expand the pathologist view of how they're looking at a particular case rather than just reporting out results. And so I and that's true in image analysis to where the image the AI could at least look at and say, hey, these are the things I'm thinking about.

So in addition I'm looking at the slide and making my diagnosis, but then I can look and see what it's thinking about. And maybe the example I've heard from Ulysses at Michigan is like amyloid. This thing we don't really look for a lot and but it occurs in vessels and it's not part of our normal Looking at every slide, should we be looking for everything? The answer is yes, but do we think of that? And that's when we're those images come up and the computer says, Hey, I think I see amyloid in this area here. That's not why the biopsy was taken. That's not the primary reason that this is being looked at. But I think I see this in a lot of the pathologists to then look at that image and say, Yeah, I think it is or no, I think it's not our order. There can go red and go on. So I think those kinds of assistive technologies, some kind of excited about that to assist us in getting to the right diagnosis.

**Dr. Mary Edgerton:**

This is true. And when people ask me if I'm worried about my job, I'm not worried about my job, I don't think a computer can completely replace a pathologist, but I would like it to help make my workflow go faster. I think actually Eric Glassy, who Tim is going to work with, mentioned one time, he'd like a digital image analysis to go through his cases and stack them in terms of which ones need the diagnosis first and might need subsequent testing not to not to write the report, but just to say that although I say if you're going to have one that's going to do your diagnosis, it should write a report also, because that's the right limiting step for me. But I think the computer human synergy is something that we should be working for, not the computer taking over.

**Dr. Timothy Law:**

Yeah, I do. I do see definitely the concern of, you know, the provider completely not using their brain, just completely relying on age. Like when you see the AI, you just trust it. Then you just let it go. Let it go. Even now, even without ChatGPT to AI, just what's just with breast prognostic marker, our Virtuoso. I'm already seeing problems because, you know, there are some people in my practice who just 100% trust that whatever you're circling is one plus two plus zero and without actually just looking at the digital slide and so and yeah and so there are problems like this when you have you as the user have to make the final decision yourself. So even with we're not even a complete AI ChatGPT, but even now we as clinicians have to be very careful even with just something is even more basic as just scoring. I see. So yeah.

**Dr. Mary Edgerton:**

Rebecca Segao-Coyle, you've been waiting patiently. Please tell us a little bit about the work that you're doing with breast cancer.

**Rebecca Seago-Coyle:**

Sure. So just a little background. So I was diagnosed when I was 35 and also found out that I was BRCA2 positive. I learned very quickly to advocate for myself in the patient advocacy world. We talk about like we may not have come from the cancer world, you know, from training, but we started jump into the deep end of it to try to learn the different things that we need to know as a patient to be to meet those data driven decisions that actually impact the rest of our life.

So having this sort of data at our fingertips to know what what our data looks , how it's going to be used and for research, I think a lot of folks, while the data we're in the current situation, there may not be the right treatment at the moment, but the data that comes from you going through this can also impact others down the road and improved therapies and different techniques, kind of like what we're talking about now.

As I said, I'm a BRCA2, I have a genetic mutation and learning I was the first one in my family to get tested. So earlier I really had to advocate to have a mammogram at the age of 35. And in fact, I actually felt the lump in my breast in a year before. But because the my family history was on my father's side, which it does matter. I was in biology in college. I know you get half your genes from each parent. So it does matter. But my doctor at the time said she didn't care about that. She only cared if it was my mother or sister who had been diagnosed with breast cancer. I've learned since then that you just you know how to advocate for myself, knowing that I am a carrier and that the different screenings and different techniques that I need to do moving forward to have the quality of life that I want. I will say that it did kind of launch me professionally into this world. So I work for health care start ups, kind of from a program management standpoint. So working with companies that also ingest a lot of the data that patients are given curation and making it available back to the different researchers and pathologists and such too to help the patients make that decision.

**Dr. Mary Edgerton:**

And I believe you do a lot of work with the Komen Foundation also.

**Rebecca Seago-Coyle:**

I do. In my spare time, I am an avid advocate and science member, which means I work a lot with the researchers they are required to have a patient advocate on their research studies. And so working with them to understand that and ensure they're thinking about the patient as well from beginning to end. So we review the protocol from a patient lens. A lot of us do not have that science degree. So in some ways it's a foreign language. But if we look at what the research is trying to do, look at the protocol, the aims and the outcomes, then we can help guide the researchers to make sure they're thinking about the right things that can have a positive impact towards patients.

**Dr. Mary Edgerton:**

And you also work with the patients in our research institute? I think it's known commonly as Cory.

**Rebecca Seago-Coyle:**

Yes, I'm also a reviewer on their end as well. So reviewing once studies have been completed or worked on looking at it and looking at the plain language summaries of it to see how that's going to be viewed from a public standpoint with a patient lens.

**Dr. Mary Edgerton:**

So the 21st Century Cures Act has required that pathology laboratories make their reports available to patients. Have you heard any reaction to that? Can you share that with us?

**Rebecca Seago-Coyle:**

I think for me, I can only speak from my own standpoint and some of my colleagues that I work with as patient advocates. But I think knowledge is power. And so having that information can only improve your way that you can advocate for yourself. So understanding the pathology of what your tumor is and what how it might react is really important because it helps advocate for, I think, Dr. Simpson, you mentioned patients will go to other facilities and be able to we take that data with us. Once we've been diagnosed, we take that data with us.

So we need to be able to help communicate to our doctors what we would like and how we can prepare for preventing additional recurrences and that sort of thing. So in the moment when you're diagnosed, it's like I said before, you've jumped into the deep end of the cancer world and it's very overwhelming. So it's hard to really comprehend what all of this means. But once you get on the other side, once you've had a break from all the appointments and surgeries and can actually comprehend what this means, then you can take that information with you. And Komen also has a new registry called Share for Cures, which you can share your data through there that allows researchers to be able to use that to help improve therapies and such.

**Dr. Mary Edgerton:**

That's really good to hear. Komen does fund a lot of very important work and both at the research level, on the lab level. And in fact, Dr. Barzilay asked, how can we figure out which of these patients are going to recur? And I was involved in some Komen funded research looking at, well, not recurrence, but actually what they call interval diagnosis. So the intervals for mammograms are something like once a year when you reach a certain age and there are people who actually develop a cancer within that interval and it tends to be a more aggressive cancer, which they found not through screening, but through being able to palpate it, which means that it was a bigger size. So trying to look at some of the factors that affect that.

**Rebecca Seago-Coyle:**

Even knowing that information too, of course we would love to have a crystal ball that says, hey, this is going to recur. This patient knows we can educate that patient how to advocate for those different things. But truth is, it depends on where you live too, in the world that that doesn't always happen. And so again, I'll come back to knowledge is really power, but also having that knowledge, you have to be mentally prepared to deal with knowing that you might be at higher risk, knowing that you might have a genetic mutation, how do you use that information to help you also live a good quality of life too, without having that cloud over you or waiting for the other shoe to drop. So just trying to balance that.

**Dr. Mary Edgerton:**

Yes, unfortunately, medical care varies tremendously across the span of hospitals and regions of this country, and that's when I get a call from people. It's just amazes me sometimes the level at which they no testing available. In fact, my hometown, I just had a podcast with a physician there who is a family practitioner, and when he arrived there in the late seventies, early eighties, there was no ambulance. And if somebody was hurt or suffering pains, they just drove them over to the little E.R. of this little community hospital. And when you read about how patients have to be handled, if they've had any kind of injury. It's just somewhat shocking. But they do have an ambulance now. They do all point of care testing and then they send samples about 40 miles away if they need more testing than that. So that shows you you just don't have that. Ross?

**Dr. Ross Simpson:**

Rebecca, I have to ask you, with the release of information to the patients and one of the controversies we have and we get concerned about it is that it gets released to the patient the same time it gets released to the doctor, and the doctors are busy people. And so we get concerned, especially on Friday afternoons, that we're going to be giving someone a malignant diagnosis Friday at 3:00. And the physician's not going to see it till he gets back from his three day weekend on Tuesday. And it's one of the areas where there's debate on whether we should be able to delay it a few days and let this to try to manage that interface, which can be, as you know, very emotional. And it's so much information and it's a breach in your patient view and that interface and how we can a little bit get stuck in that. And we're worried we're not doing the patient and we're leaving them maybe emotionally struggling over a weekend, for instance.

**Rebecca Seago-Coyle:**

Well, I kind of have to laugh a little bit because as someone who was told that they had cancer on a Friday afternoon and don't Google it. I think communication is really key. And setting those expectations. You don't want someone to spin. I mean, I always say, how would you want your information to be communicated to you? Do you want to find out on a Friday afternoon? I mean, it is what it is. It's not going to change anything. But we're all human at the end of the day. I think that's the main thing that we have in common. And so treating her with kindness and respect, knowing you're just about to disrupt someone's life. Personally I like having my results. So I like to be prepared to have the conversation with my physician. But it is I mean, the moment that they called me on that Friday afternoon and said, your results are positive, you have cancer. It's like my world was flipped upside down. It was like I had different plans for that weekend.

**Dr. Ross Simpson:**

And I do think, you know, you get called when I'm worried about more as the ones and we put it out as a pathologist that the patient gets it on their chart in their iPhone and no one calls them. So they don't have anyone to talk about what the next step is. And those are the ones I worry a little bit about. I'm actually for the patients getting the results as fast as possible, but I worry about that interface when it's not personal.

**Rebecca Seago-Coyle:**

Well, I think too I mean, there's two different ways to think of about it. I mean, one yes, patient. The proactive patient is looking at their phone. They're looking for those results, too. You know, if you do have to give some bad news like you have cancer you might want to be a little more thoughtful and like delay it. But also, if they if the patient is expecting those results, they're going to spend like, why haven't I gotten it? Clearly, it's the bad news.

**Dr. Ross Simpson:**

And that's kind of what I've shared with my colleagues that are concerned about that and clinical side is that to prepare the patient to know that they might get the result before they do, when there might be a few days delay in lot of times just from the mammogram, etc., there's a high probability. So they know that there's certain things. So I tried to set it up that way. So at least everyone's on the same plane.

**Rebecca Seago-Coyle:**

Not to keep sharing my own journey, but I will say from when I felt the lump, my doctors, everyone was, not the pathologist, but the radiologist, they were like, this isn't cancer. You have nothing to worry about. So when I got that call, I was actually on a conference call for work and I put it on mute because I was like, This is going to be quick. They're going to say everything's fine. I quickly had to get off that conference call and deal with the call that I got and just trying to wrap my head around what they were telling me. So it was a little bit of a shock, but I still think as much as you can help educate and prepare people for that ahead of time, then the patients can have a better like be more receptive to the information that you're sharing. Like I said, your world is just flipped upside down. Something that you're not expecting, especially for those of us who've been diagnosed at a younger age. We're expecting to get married, have babies like that sort of thing. We're not expecting to have to go through cancer.

**Dr. Regina Barzilay:**

I just want to opine on the last point about not getting information for the patient. I was at MGH which was considered to be the best of the hospitals. I really cannot say that I got some information on my initial diagnosis from the doctor that I didn't find on Google because when we're talking about standard diagnosis, we're talking about something which is very unique for many things. You can go and query. And for those of us who went through biopsy, you are not resting for one second until you get the result.

And even you can say, Oh, why would you do it on Friday? Let's do it on Monday morning. Rebecca, maybe in your case, because they falsely told you that everything is okay, but who exactly can sit down there and relax and celebrate that we can visit family when they're waiting the results. So I think the soon as at the moment that the results are available, the patient deserves to get them. And some people may decide that it's their right and they would like to do it. So verbal conversation with a provider and one can, you know, provide them with this option if that's their choice. But the vast majority of us who really waiting for this result have to get it as soon as it is available. And I'm not only sharing my experience and sharing stories of so many of the patients that I met in the last nine years. So this will be my advice share soon as they are available, even if it is through the phone interface.

**Rebecca Seago-Coyle:**

Well, I think too, if you are a pathologist and you are getting those results and then you need to be able to share that with a doctor. If the doctor is knowing that there are some results coming, try to plan ahead and reach out to the patient as soon as possible, just like you said, like it. We are spending we are waiting for those results.

**Dr. Ross Simpson:**

And we do. What we set up is the doctors were just too busy. So we we have our our breast center has nurses that work in this format. So we paid to the nurse at the time that we sent this, we sent on the case. So they try to call the patient there that within that hour.

**Dr. Mary Edgerton:**

That's really fascinating. They're really different points of view. I know I want to know everything at once, but in it there is an emotional side to me, no doubt about it. But also I have access to search engines and I know how to find the ones I like. And beyond search engines, you know, to literature that I can read and understand. So, I mean, I think we've lived in a paternalistic medical society in the past where people didn't even know their diagnosis when they were dying. And I remember cases like that, don't say cancer in front of him. He doesn't know he has it in times of change.

**Dr. Ross Simpson:**

You know, I'm definitely in agreement that we need to really see results. Right. I remember the old days. They wouldn't be released until the doctor released them. We'd have things go on for like pap smears. It would be 30 days and they would never pass any result. It's just like, What the heck are we doing?

**Dr. Mary Edgerton:**

Right, right. We could go on forever. But I know that our is coming to an end. This is really been a great podcast and I really want to thank all of you all and all for chiming in that those were all really very important points and, and then thank you all again for participating and that I'm going to hand things back to you.

**Becca Battisfore:**

Thank you, Doctor Edgerton, and thank you to our guests for sharing your expertise and experiences, especially this month, as October has been recognized as Breast Cancer Awareness Month for nearly four decades. And I want to thank you all for listening to this CAPcast. You can find links to the CAP’s Cancer Protocols in the episode description. And for more information about the CAP, visit CAP.org.