# Pathology Reports: Can One Size Fit All Stakeholders?

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**Lisa Tomcko:**

Welcome to the latest edition of the College of American Pathologist CAPcast. I'm Lisa Tomcko, content strategist with the CAP. Some pathologists embrace direct engagement with patients. Others prefer to communicate through the patient's primary care doctor or ordering physician. In this episode two, leading CAP members explore how we engage with patients, particularly through pathology reports.

I want to extend a big welcome to Dr. Diana Cardona and Dr. Harry Hwang. Dr. Cardona is a governor on the CAP'S Board of Governors, an advisor to the committee that oversees the CAP'S clinical data registry. She's also lead investigator for the CAP'S two phase CMSS grant, which aims to improve our understanding of the patient experience with their pathology report, which incidentally is a great jumping off point for today's discussion. Joining her is Dr. Hwang, a molecular pathologist and member of the Professional and Community Engagement Committee.

Thank you both for being here. Would you like to introduce yourselves?

**Dr. Diana Cardona:**

Thanks, Lisa. So as you said, my name's Diana Cardona. I'm a practicing pathologist for AP and CP at Duke Health. We, in addition to doing primarily GI liver, bone and soft tissue pathology, I'm also vice chair and director over anatomic pathology laboratories and the assistant director for clinical laboratories across the house. Within the CAP, as you mentioned, I'm a newly elected board of Governor and vice chair on the Council on Government and Professional Affairs. But previously I served as the chair of the Quality and Clinical Data Registry Committee, as well as vice chair of the Economic Affairs Committee. And with that, I will hand it over to Dr. Hwang.

**Dr. Harry Hwang:**

Thank you, Diana. My name's Harry Hwang. I'm also a practicing pathologist. I am the chief medical officer and medical director at PhenoPath Laboratories in Seattle, Washington. We are a primarily oncology focused pathology reference lab, and we handle biomarker studies and solid tumor as well as diagnoses in both solid tumor and hemology type specimens. And I'm also a member of the CAP Professional and Community Engagement Committee, so it's a pleasure to be here today.

**Lisa Tomcko:**

Excellent, welcome. And with no further ado, I'll let you both take it away.

**Dr. Harry Hwang:**

Dr. Cardona, congratulations to you and CAP on the grants, particularly on the ones that are in reference to our topic today. And I was wondering if maybe you could perhaps start with telling us about the grant awards that you have and the type of work that you have been doing in this area.

**Dr. Diana Cardona:**

So as you mentioned, the CAP, we were awarded two grants from CMSS, which is the Council on Medical Specialty Societies. The first one was really focused on trying to get a better understanding of how patients interact with our pathology reports and what their current experiences are. And then the second one is building off of that, really more focused on taking the learnings from phase one and exploring how maybe what we learn from that impacts our other stakeholders. There are a lot of different stakeholders that really rely on our pathology report to meet their needs, whether that's oncologists, surgeons, radiation oncologists, even radiologists, as well as insurance companies and quality reporting registries. There are just a lot of different individuals that look to our pathology reports to meet their needs. And at the core of all of it though, is the patient. And so are we really crafting our reports to help meet the needs of all of those stakeholders?

And that really was the intent of both of these awards. Now, I've received a lot of questions in the past as far as like, well, why is the CAP looking at this or specifically why the committee focused on the Quality Clinical Data Registry was looking at this. And it's really twofold reasons. One was with the implementation of the CURES Act, patients have ready access to all of their medical record data, including pathology reports. And I know in my own practice, I kind of shifted a little bit after the CURES Act before I was always focused on what is it I'm trying to communicate to my referring clinician, whether it's a surgeon, oncologist, GI Doc, whoever. Now after the CURES Act, I actually think about, well, I need to effectively communicate with those same individuals, but then I also have to keep in mind the patient who's going to be looking at this report and making sure that whatever I'm writing in there isn't causing undue stress or maybe more confusion than there needs to be.

And the other thing is the Institute of Medicine, especially after multiple reports on diagnostic errors, they really are focusing more on this kind of patient-centered care. And they've demonstrated that the more readily patients can engage meaningfully with their care plans, with their care teams, the more opportunity there is for reducing errors. And I think that now that patients have access to our pathology reports, that offers us another opportunity to ensure they understand what's happening, they understand their diagnosis so that they can more effectively participate in care decisions that they need to make. So I think those are the background a little bit and the focus of the two awards.

**Dr. Harry Hwang:**

And I think that from my standpoint and my practice is based in a pathology reference lab. I guess taking a broader view of your work, there are maybe three different settings. There's the community hospital setting, there is the private practice/private lab setting, which I operate in, and then there's the academic setting. And so I do think that I, one good outcome of the CURES Act is to support patients as a major stakeholder, obviously in the report and trying to look at the reports that we generate. With that in mind, in addition to conveying the information to the clinicians, you had mentioned that you have started to try to incorporate some of those ideas. Can you touch on any things or examples of changes that you may have implemented since you've engaged in these studies and taking into account the CURES Act?

**Dr. Diana Cardona:**

I can maybe share a little bit so far what we've learned. We just somewhat completed the first phase, really learning more about patients interactions and their experiences to date. And we just kind of kicked off the second phase, creating a technical expert panel with other clinicians that rely on pathology heavily. But just to kind of go back on the first phase or the first grant, what we did was we focused on patients with colorectal cancer and we first sent out a survey for people to participate. And it was a short survey really just saying, did you see your pathology report? If you did see your pathology report, how easy was it for you to understand it? Did you like the layout or the organization of it? Some very basic questions just to kind of get a sense of their experience. And then we asked them more specifically, what would made it better for you?

What would've been helpful? And that part was interesting to me. I think that what wasn't surprising was that the majority of patients felt that understanding their report was difficult. And I don't think that most pathologists or clinicians would be surprised by that fact. What I expected them to say was that, well, it would've been better if you just summarized it in a, they always talk about fifth grade, fifth grade level reading, right? Trying to create terminology and verbiage that most reading level acumen could understand. But in fact, that's not what they wanted. They didn't want us to change a single thing about the report, but instead they wanted us to provide them either some explanatory sentences or maybe even a glossary of terms for them to understand the terminology that's being used in their pathology report. So after the survey, we actually underwent a couple of one-on-one interviews with volunteer patients as well as two focus groups.

And diving into that, well, why don't you want us to change your report? What they unanimously said was like, "No, no, no, no. Don't change what you're communicating to my care team. I just want to understand it so that when they're using those terms, I know what they're talking about and then I can better engage in those conversations." And additionally, they were even saying, "If you could tell us what happens next, what should I expect?" Because there's usually this lag of time between they see their report now, they literally can see it almost immediately versus when they actually have the opportunity to meet with or speak to their surgeon, GI doc oncologist, whoever it may be in that time period, is there an opportunity for them to be reading, looking at additional resources, et cetera. And so that was another thing that they mentioned, well, if you can't do a glossary of terms, could you at least give us links to other things that we could read up on and learn and do our own investigation?

So to go back to the original question of like, well, what am I doing personally in my practice? I will say that I haven't added a glossary of terms yet. I haven't really changed much in the way of formatting or anything like that, but I am more cognizant of not putting too much fluff or what we used to be taught, put on all these pertinent negatives. And I actually asked myself, well, why am I putting in that in my reports? It's really just to help mitigate a phone call later or just to tell whoever the authorizing provider was like, yes, I did look for eosinophils or whatever it is. But in fact, the more you add all those things, the more questions and confusion it might cause to patients. And if I have an opportunity to explain something just a little bit more, I do do that as well, both for the patient.

And to be very honest, I would say most of our providers don't understand our reports often either. And so it serves as an opportunity for us to educate them. So that's what I've done so far. I will say that at Duke though, we are exploring some other tools that we can utilize in our MyChart access. We are an Epic House, patients access their reports and their medical records through MyChart. We are in the process of creating a tool that will allow the patient to somewhat maybe interact more with their reports and actually hover over terms and have a definition pop up or an image of anatomy site, for example, pop up. So we're very excited about that. We're in the early stages of it, but we're hoping that that will really help drive the needs that we're hearing from the patients, especially in light of just learning what these terms mean.

**Lisa Tomcko:**

We're going to take a quick break from today's episode to talk about an exciting new program from the CAP, now open for registration. When it comes to successfully starting a new job, preparation is key. Introducing the Job Prep Bootcamp from the CAP, a fast-paced, interactive virtual review designed just for pathologists like you. Refresh your skills in signing out less familiar cases, access the library of resources to ensure thorough and accurate case workups, learn to recognize and avoid common pitfalls, get guidance from experts, and tap into a supportive network exclusive to the Job Prep Bootcamp alumni community, you can find the link in the episode description to get more details and register. And now back to the episode.

**Dr. Diana Cardona:**

So I'm kind of curious, from your practice setting, has the CURES Act done anything for you? Are you noticing a difference in how you're having to communicate or maybe even interact more with patients?

**Dr. Harry Hwang:**

Yeah, that's a great question. And we also try to be as concise as possible in our reports. And as you refer to, try to avoid overloading the report with so-called pertinent negatives. And I've also heard in looking into patient reporting that as you kind of alluded to, that can cause a lot of confusion and possibly unnecessary anxiety by bringing up things that perhaps are in the specimen and saying that it's not there can raise red flags to a patient saying, "Oh, so you're worried I do have cancer." And I think by leaving them out, it helps with reducing that type of response. We also put in our reports, we try to put in references, but not too many. And I suppose that can be a resource to the patients given the ability to access papers or at least abstracts to references, medical references, that can be helpful.

I am curious about your glossary of terms and how you're thinking you might implement that. Would that be part of a different section in our immunohistochemistry reports? In addition to comments safe for PD-L1, we put in the indication reference and maybe refer to the FDA approved language. And also at the end we also put in our immunochemistry reports, a small section that defines the use of these antibodies. And it's at the end kind of as a little appendix. So what kind of, would a glossary maybe fit in there? Is that kind of maybe what you're thinking about doing?

**Dr. Diana Cardona:**

I've definitely seen a lot of private vendor reports in which at the end, they kind of either describe what the gene usually is seen in or what biomarker usually signifies. So I think that that definitely is helpful from an education standpoint. So I could envision a glossary of terms doing or fitting somewhat similarly in a report as well. And so as I mentioned for the first phase, we did the survey. We did one-on-one interviews and the focus group, we actually showed patient groups a couple of different options for what a pathology report could look like. We had one where it was like, here's the full report. But at the very beginning there was this little kind of abridged summary, one or two lines. There was another one that was, here's the full report, but there was a much larger, a couple of paragraph summary with also describing what the next steps would be.

And then a third one was, alright, essentially the same type of pathology report where we've got specimen 1, 2, 3, but the first line of each of those specimen was just literally a one-liner that says, "This is part of the intestine, negative" or "There was no evidence of a tumor." And then the second one was like "This was part of the intestine that did have evidence of tumor." Very short summary of what that section or what that part was like by far the most popular one was that third one where the report essentially was still the same, but while there was added to it was that one liner just summarizing what that section was saying or kind of describing as far as relevant to the patient. And then the second focus group was when we took that report, that was kind of the favored one from the first focus group.

And then we showed them like, all right, well what about a glossary of terms with that report? Or what about a glossary of terms with just some helpful links, whether it's cancer.net or yourpathologist.org, which is a CAP site, my pathology report.ca, which is a really good Canadian website. If you've never seen it, I would encourage you to look at it. Or a combination of all of the above. And the patients really loved all of the above. Having the report with just a mini little one-liner for each part that kind of just summarizes what they needed to understand, plus the glossary of terms and the resources for them. They didn't like the huge kind of summarized version with multiple paragraphs because then again, even at that time when we're making the diagnosis, we may not know all the different caveats to that particular patient for us to really know what they're going to do necessarily next.

And so a lot of the times we felt that the recommendations would be very generic anyways, and they could see that they're like, "Well, this really is too generic for it to mean anything to me." So they didn't find value in that, which I also thought was kind of interesting. So yeah, to go back to the glossary of terms, I think that at a start, it could be something that is appended to your report and maybe only viewable through whatever access point patients are looking at the reports through. I think that this is something, once these grants are finished and we come up, hopefully with some, there might be actions that the CAP could even take. Could this be a resource that the CAP could build and pathologists could then grab it and link it to their report or just add that list of references and say, click here for a glossary of terms, right? And it sends the patient to the path or the CAP website, for example. So I think there are some maybe low hanging fruit that we could maybe try to help support pathology practices so that we don't create too much burden. But then I do think that whether it's AI or some other software tools that are going to come down the pipeline, I'm hoping that there's other players in this space as well, because again, I really truly believe that the more we can educate patients, the better equipped they are to make informed decisions.

**Dr. Harry Hwang:**

Yeah, thanks for that. And I agree. I think maybe what you're getting at too, I mean the CAP does have on their website in terms of directives for how to report the different aspects of different diagnoses and maybe the CAP can, after going through this process, could provide templates for use for different reports that are kind of basic that maybe show where you would put those single lines to. Maybe that goes somewhere near the micro section or it's its own section after the comments. Or maybe that would be a way to do it. The CAP could provide after vetting it templates for different report formats and then have that as a resource because it could also have in these report templates, the links you mentioned and the fact that someone with your background and work in this area and others, it'd be something, a very good resource for the CAP members and pathologists and non-pathologists who use these resources to access would be quite valuable because I think there is a willingness and a desire to make reports more patient, friendly and usable. And I think it just can be difficult to know a format to start with.

**Dr. Diana Cardona:**

Yeah, I agree. I mean, I've had the opportunity to share some of the data from the first grant and some public venues, and I was surprised, pleasantly surprised with how overwhelmingly positive of a response I received. Pathologists in general really do want to make sure that they're meeting the needs of our patients, but similar to the initial kind of cautious stepwise progression that we're doing from the committee's perspective, when they reviewed it was really just the question of, well, how are we going to do this in a way that doesn't kind of just fully put all the burden on the pathologist. Because we're all pretty stretched thin, and although we love templates and our CAP templates and cancer reporting, it's just gotten more complicated longer reports. So how can we do this without just, again, creating more burden on pathology, but demonstrating the value. On the flip side, I think it's a great opportunity for pathologists to be at the forefront.

It's often that we're behind the scenes, and this really provides us an opportunity to help interact more with patients, even though if it's not direct conversations, this is a way that we are communicating with our patients. And so how do we do that in an effective manner? I think in the end can only serve to benefit us as a specialty as well. One of the things that we were also curious about is, well, if we did change our report, if we made it longer, if we changed the organization of it, et cetera, how would that impact the other stakeholders that I spoke about earlier? And I'm just curious as to, do you think that if you did change your report or added more to it, would you get pushback from any of your referring providers?

**Dr. Harry Hwang:**

As long as it didn't add too much volume to the report, I think it would be fine. And as long as it's organized in a way that at, near the top, where the specimen is designated and whether it's an interpretation or a biomarker result, as long as that's clearly delineated at the top, I don't think it would be a problem at all. And what you described as the preferred format was actually sort of more on the smaller side in terms of additions that were preferred. And I think that is implementable. And I also think there is definitely a role for pathologists and the CAP, and perhaps you could formulate a checklist item to say that the group or the medical director is looking at this, do you review the report in regards to patient accessibility? And so I do think there is an important role that is the first way in which we interact with not only clinicians but the patients. One thing I did want to ask too, since this is on this topic, isn't related in some regard to how pathologists interact with patients. Have you seen in your practice setting more direct asks for requests for patient reports directly through your pathology department? Have you seen an increase in that since the CURES Act? And how have you, your lab staff dealt with that?

**Dr. Diana Cardona:**

I would say that the vast majority of our patients do have access, and they get their reports through the Epic MyChart. So I'm not seeing requests necessarily for reports, but I definitely have seen maybe a small increase in the number of phone calls that I do receive from patients asking questions. Orthopedic oncology surgeons, they know that whole team knows that I'm willing to actually meet with any patient if they're interested in it. And that really, I think for me, solidified the importance of making sure patients understand what's happening. Sometimes it's so powerful to put a face to the name. So even just seeing their tumor and why we're calling it that, you can just see the light bulb in their eyes kind of like, oh, but I've had some really great conversations with patients too, understanding when we have satellite foci of tumor, that's why they're recommending that you have postoperative radiation.

And when they actually could see what that means and that, "Hey, even though the margin is negative, but you can see that this little focus of a satellite tumor is so close to that margin and I can't tell you what's on the other side of that margin," then it makes sense like, "Oh, then maybe I should make that decision to choose radiation," or "At least I can make an informed decision that although I understand the risk, I don't want to have radiation." So having those conversations and really allowing the patients to understand more what their pathology actually means can be just so powerful for them. So yeah, I definitely, it's not often, honestly, it's probably less than 10 times a year, so it's not a huge burden yet. But I definitely see the reward for me even. But as well, for the patient, I will say that there are some faculty in my department that have gone to the point where they put in their office line in their reports now, like "Should you have any questions, please feel free to reach out."

You can even schedule an appointment with me so that they're more actively engaging in a way encouraging patients to call if they have any questions. I would say that the vast majority of our neuropathologists, for example, have that in their reports. But I do wonder if there are maybe some better ways for us to do that. If we were inundated with phone calls, then obviously that's not manageable because A, we're not really getting paid for that unless we wanted to create chart notes and EM codes and all of that. So if it did become to a point where it became overly burdensome from a time perspective, then we would definitely need to maybe do something to mitigate that. But I think that this, and thinking about how we do our reports to meet the patient's needs would be one way to do that.

**Dr. Harry Hwang:**

Yeah, I've also have rarely been called on by patients to discuss within the reports I've been happy to do so sometimes a conversation kind of addresses things that it's difficult to get on paper even if you try to make up a glossary of terms to address things. And I think just having that as part of what pathologists offices are willing to do is helpful for the profession. I think one thing that comes up is in addition to utilization, and we have to watch how often we are asked for this is also training for this and handling these conversations with patients. And maybe that's something to consider that maybe the CAP can address. I do know that in the few conversations I had, what was helpful is kind of try to be as empathetic as possible at the beginning and so forth. If they say that, yes, I have this report, I had some questions, and if you say, oh, what is this? And you find out, it's like, well, I'm very sorry that this is happening. I'll try to help you as best I can by answering your questions." And I think that went a long ways to making it a very productive type of discussion and that addressed the patient's concerns and questions without taking the undue amount of time.

**Dr. Diana Cardona:**

The more we could educate our patients on the value that pathology and laboratory medicine provides them, the stronger our profession will be and the patients would be on our side and help advocate even on our side when needed. So I think that's quite powerful. As far as education, that's definitely one of the focus items for these grants is once we get our learnings from the various activities, is sharing those learnings and sharing recommendations that come out of it. So doing that at various meetings, we hope to hopefully write a manuscript about the work, but then at that point, it really is how we implement it at the practice setting and at the academic centers, how we educate our new incoming kind of pathologists. And those are the conversations I have at the scope with my trainees all the time. "Well, what is it that you're trying to communicate? And to who?" And I think that's just part of that discussion and that ongoing changing our mindset a little bit of who is our customer, who is our audience for our reports, so to speak, and making sure our report meets the needs of all of those various stakeholders.

**Dr. Harry Hwang:**

And I think a lot of this will get, is going to be more of this, right? Because with advances and targeted therapies and personalized medicines, it's actually an opportunity for we as pathologists to help patients understand the implications of some of these tests. Oftentimes, it can be single gene tests, but it oftentimes can also be more complicated NGS panels that unturn a large number of findings, some of which are relevant to the patient's therapies and some maybe not so much. And I think some of the ideas that you bring up are going to be applicable to new reporting of new biomarker results for new therapies in addition to anatomic pathology traditional diagnoses.

**Dr. Diana Cardona:**

Yeah, I think you hit the nail on the head. Honestly. I think it's such a huge opportunity for us. Precision medicine, access patients have now, all of this really provides us an opportunity to think about how we do things a little bit differently and hopefully a little bit better. This concept of patient-centered pathology, that's really new for us. But I do think it's such a huge opportunity that we should harness, and honestly, if pathologists aren't the ones figuring out how to do this, then others will figure it out for us to be very honest. And we'll either be carved out of that process or be told what to do in potentially a way that's not considerate of the burden that it would put on us. So pathologists really should be the ones leading the charge in regards to how we ensure that we are providing patient-centered pathology.

**Dr. Harry Hwang:**

That idea also comes down to when we get test requests at our lab, we look at the requests and also the diagnosis and the patient history. Especially in the early months when new therapies are approved, there's sometimes confusion on what indications are appropriate for testing. And we all know that medical dollars are finite and we're all trying to be efficient and not testing and not doing unnecessary things. And so one thing that, one experience we've had in the past was when there was a testing indication in breast cancer that was dependent on stage, it was interesting because even in the pathology report, and even if it has some medical radiology information, you could not always delineate what the stage was. And a lot of therapies are suited, suitable for certain stages, but not other ones. And I think that might be an area where, in addition to the pathology report being clear and giving guidance on where you can find that information, not just the biomarker result, but where to find what your stage is.

**Dr. Diana Cardona:**

And I think that hopefully with this second phase of the grant, we learn a little bit more about, well, okay, we're going to figure out ways to help meet the needs of the patient, but are we actually meeting the needs of our clinical colleagues? I would hope that we would hear back from them if we weren't. But I think that the example that you just gave is a perfect example where, alright, well maybe it's the organization of the report, that's a little bit too complex. If we're not using synoptic reports, maybe it's not very clear for the audience. Sometimes it's even the formatting, right? Our report in our LIS looks exactly how we want it to look. It is perfect, the layout, but then as soon as it moves out of our LIS into someone else's EMR, the formatting changes. And sometimes you don't even know what it looks like on the other end, but it can be really confusing for the end user.

So I think there are so many different things that are at play here. And so again, we're hoping that with the second phase of the grant, we'll be able to learn more about the other various stakeholders and how they currently interact with our pathology reports and what we learned from phase one. If we implemented those changes, would that be negative impact to them or not? Or actually help them in their day-to-day work as well, and the way that they can communicate effectively with their patients. So yeah, I think that's exciting. There's so much opportunity here and I do hope that people view it in that way and not as a threat or as it's just one more thing that we're going to have to do. I think if we do it correctly, hopefully it actually mitigates downstream work and really just helps us effectively communicate.

**Lisa Tomcko:**

Thank you both so much for sharing all the great insights. We've heard about research-backed findings from patients as well as your own personal experiences with pathology reports. I think we're all eager to see how pathology reports evolve to meet the needs of both patients and their clinical care teams. Thank you both. Again.

**Dr. Diana Cardona:**

Thank you. This was a lot of fun. Yeah, thanks for having us.

**Lisa Tomcko:**

And a big thank you to our listeners as well as mentioned by Dr. Cardona. The CAP has a website for patients called yourpathologist.org. Look for the link in the resources section of the show notes and stay tuned for future episodes of CAPcast. For more information about the CAP, visit cap.org.