

AHRQ National Webinar on Advancing High-Value Pediatric Care:  
Using Data, AI, and Family Engagement to Improve Outcomes  
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[Inform Shared Decision Making with Advanced Bayesian Causal Inference to Improve Quality of Pediatric Rheumatology Care](#)

**QUESTION:** What potential challenges do you consider in presenting prediction of patient treatment outcomes to patients?

**ANSWER:** That it is a little tricky, and some of the information may feel a little intimidating. There are already some misconceptions that arthritis in childhood only occurs during childhood and then goes away after a few years. We know it is a chronic disease. So, in some ways, having this evidence-based, real-world information that allows us to present grounded data may go a long way in building trust. While it may feel a little scary, it is really important to have real-world data to share. We are in an environment where there is a lot of information available on the internet. This is actual real-world evidence that we can share, and that is super helpful.

I do think we have to spend some time working on getting the verbiage right around how we share this information, especially while there is no cure and we are still working toward cures for these chronic diseases. This really just provides more insight into getting to the right treatment faster, rather than slowly incrementing treatment over time. As things fail, we will have a better idea of what is more likely to work.

**QUESTION:** Could you describe how this technology might be scalable to other conditions?

**ANSWER:** I can think of other use cases, particularly in other chronic illnesses and conditions where there is continuity of care and the use of standardized disease activity assessments and care. There are examples of learning health systems across various chronic diseases that already use standardized data capture. So, this approach is wide open to applications in inflammatory bowel disease, nephrotic syndrome, and other similar conditions, where the same kinds of computational algorithms could be developed pretty readily.

**QUESTION:** Can you describe how this approach might be used in primary care in addition to tertiary or specialist care like pediatric rheumatology?

**ANSWER:** That is a really interesting question, and it is somewhat predicated on having a diagnosis for which the algorithms have already been created. I think the development phase will involve going diagnosis group by diagnosis group to create the models. So, I could see it being used in primary care, particularly for conditions with heterogeneous treatment effects, where we expect that people are not all going to respond similarly to the same medication. It would then require a large dataset with structured data elements so that we could run and develop the models for that condition. So, it could potentially happen. There would also need to be a commitment to using the tool in practice, along with some training. It may help if there is a practice-based research network or something similar interested in taking that on for a particular condition, and then I think it could be applied.

**QUESTION:** Dr. Morgan, in trying to identify commonalities among patients, are you only looking at clinical presentations or are you including other information such as laboratory values, x-ray results, social determinants of health, genetic information, etc.?

**ANSWER:** I wish our statisticians could be on this as well, but I know there was a lot more that went into the model than what we ultimately boiled it down to in the end. For instance, the amount of morning stiffness, uveitis, and labs were all included in the original model but were distilled down over time. It is a great question and something that needs to be considered with each patient group as the models are being developed. I also mentioned that the models are flexible, and that is something worth testing over time. Perhaps some of that data just was not available. For instance, in a single center, you probably have a more limited diversity of patient experiences. Expanding this on a broader scale offers the opportunity to incorporate more of that data. It is a really, really good concept that we should continue to explore.

**QUESTION:** Tell us what you're most excited about for next steps in your research?

**ANSWER:** Really just getting this out into the clinical setting. We have been doing a lot of testing and bringing it in front of patients to get more of their input and better understand how this will help with their decision-making and hopefully provide value. We really cannot wait. We will continue doing that while refining it further. We would really like to make this a clinical tool that can be used to help our patients.

**Sareen S. Shah, M.D**  
**Cedars-Sinai Health Sciences University**

**[ML-ROVER: Machine Learning to Reduce Laboratory Test Overutilization](#)**

**QUESTION:** What surprised you the most about the focus group findings?

**ANSWER:** One of the things that was surprising to us was how much hesitation there is around the use of eventual AI agents in the clinical space or the amount of reassurance that providers wanted that there would be appropriate guardrails. This was just surprising to us given the amount of general excitement there is everywhere for AI, but there is also a lot of hesitation. We don't currently have plans to roll out an AI agent, but things will be changing in next few years, as I think we are all seeing. If this is a pathway forward, then that is something we are going to have to think very deeply about.

**QUESTION:** There is some tension between the idea that best practices may actually vary across institutions, whether to use as-needed versus standing orders, versus the potential opportunity to standardize, with a capital S, and make things more uniform. Can you talk about that tension, and what opportunities you're seeing around clinical decision support to drive more uniformity to the degree that pediatric intensive care unites (PICUs) actually want it?

**ANSWER:** One of the nice things about being in this collaborative is that it prevents us from being siloed; that is what I'm seeing at Cedars-Sinai and what Dr. Dziorny is seeing at the University of Rochester. We have a huge pool of people to eventually beta test our prototype and say, hey, what do you think about this eventual product? With the pilot site, we'll work more in depth with that team to try and figure out what they specifically need. But we are intentionally building a framework that will be generalizable, while using the data from the focus groups. The framework can then be adapted to the individual workflows that matter for a given site, without being pigeonholed just to that site.

**QUESTION:** In machine learning, the most critical component is data — it is the input that drives results, and poor quality data can compromise the entire model. How do you ensure the quality of your data?

**ANSWER:** This is a really important issue. If you have garbage in, you get garbage out. I happen to be the lead for the data quality and harmonization subgroup of the PICU Data Collaborative and can talk a little bit about what we do on the collaborative level to ensure as high of data quality as we can get with this much data. Individual sites will submit their raw data to the cloud infrastructure. After an initial back and forth with the site to ensure there is no protected health information (PHI) that is submitted, we move on to actually doing quality assurance (QA) and harmonization for the data. Our team at the VPICU generates summary statistics for all the unique source names that it finds for labs, for vitals, for medications, and for interventions. Then, individual principal investigators (PIs) will go through those lists and pair off with another site as a cross-reference validation step to assign individual source names to common data elements. These are our concept mappings or name mappings.

Next, the Data Quality and Harmonization Work Group goes uses a framework called the Kahn Framework for QA to assess how complete the data is, how well does it conform to our schema, and how plausible the data is as well. Then we set data types, canonical data types, canonical units and limits. We do more harmonization using the string variables and we map them to a canonical list of accepted values. For the numeric values, we convert the strings and inequalities as needed and then we do unit conversion at the end. So, this leads to our eventual harmonization data set. There are still active problems with our data set, but we maintain an active GitHub where individual PIs will submit any data issues so they can be resolved either at the collaborative level or at the site level with the next submission. Hopefully, that gives some more insight into the quality of our data.

**QUESTION:** How do you intend to increase consistency in your models? Have you used them in everyday use in other hospitals or clinics, as experimental settings are not very useful?

**ANSWER:** This is a great question and a real issue in the machine learning literature. There are countless cases of groups developing a model, running it at their own site, achieving strong results, and then when they actually publish external validation findings, discovering that it does not generalize as well as expected. We anticipated this problem from the beginning and structured our experimentation to address it as much as possible.

Again, we are a multi-site collaborative, and we are doing both a temporal split (meaning across time) and an institutional split. For example, if we have data from 2012 to 2022, we might train and validate on 2012 to 2020 data only. Similarly, if we have 19 sites, we might develop the model on just 14. So, we could leave sites that the models have never been exposed to as future years to try and get at how things change over time and how things change in different settings as well.

In addition, for the next phase of the project, we will conduct a blinded prospective evaluation in which we are no longer tuning the model. We will ask PICU Data Collaborative sites to submit data on a regular basis and monitor how the model performs going forward, thinking about what real-world deployment would look like. This is not perfect still, because our PICU Data Collaborative is all tertiary and quaternary care centers, so there is a bias towards that in our data. We would need to have more community-based hospitals if we were to try and roll this out and we would likely need to develop models in those settings before we could feel confident in the results. There is still a lot of value because literature has shown that academic institutions

tend to do a lot more laboratory test ordering than the community settings, so I think that is okay.

**QUESTION:** Tell us what you're most excited about for next steps in your research?

**ANSWER:** We are excited about actually getting the tool out there. I don't know if this counts as next steps because our timeline is still three years away before we get to the pilot study, but I think that this approach that we're taking with developing a machine learning approach in conjunction with thinking about the implementation simultaneously is not something that we've seen very much of. We're hoping that if we can get the tool out there to the pilot study and that we're effective, then we've developed a blueprint that other people in this space can follow to develop similar tools.

**Michelle Kelly, M.D., Ph.D.**  
**University of Wisconsin School of Medicine and Public Health**  
**[Getting on the Same Page: Leveraging an Inpatient Portal to Engage Families of Hospitalized Children](#)**

**QUESTION:** How has note-sharing with families impacted your own workflow or communication with caregivers?

**ANSWER:** It has more so impacted us in the release of labs. I will often say "We are waiting for this lab value to come back before we decide whether you are going to go home. You may see it before I do and if it looks like this, then you can let your nurse know and we will get you out of here before I am done with rounds. However, if it looks like this, well, I will need to come in around this time and talk with you some more." This allowed me to preempt some of the discussion as they're waiting for lab results, as I am sure some of those folks do in the outpatient setting as well.

**QUESTION:** What are some of the biggest barriers you had rolling out Bedside Notes at your institution?

**ANSWER:** I think one of the biggest barriers was fear, in terms of healthcare providers being afraid that this would confuse their patients more and that it would interfere with their workload. As a consequence, there would be a lot more questions, and a lot more unfounded anxiety around that. There were a very small number of patients who had very serious questions about what was in their child's chart, which you could argue was maybe a good thing, although not always. I think that it was really important that we measured clinicians' experience pre and post. I didn't present that data here, but largely there was a lot of fear before, which recovers post implementation.

**QUESTION:** How do we make the information in notes more accessible to families with limited health literacy?

**ANSWER:** We purposely sampled those who had limited health literacy and those who did not in our interviews, and we compared those groups. We found that there was very similar enthusiasm across groups.

Those with limited health literacy were often encountering the terminology for the first time, whereas those with stronger health literacy were using the notes to check for errors; they already knew the language and were taking that next step. In many cases, families are learning our vocabulary in real time, typically during a 10-minute rounding visit. So yes, we could do

better with plain language, but families are also learning alongside us, and they valued that. They demonstrated that having access to notes with complex terminology increased their trust.

I do think AI will allow us to leverage these functionalities to translate notes into plain language. That is already happening in the outpatient setting, and I feel optimistic about where it is headed.

**QUESTION:** More healthcare providers use AI generated notes; how do you think the accuracy of these notes will be done so that misinformation is not spread?

**ANSWER:** This is a great question and very timely. I think it is actually less of an AI-specific question and more about note quality in general. When we first discussed sharing notes with patients and families, our providers said, "We cannot share them. You know how bad they are." When I asked what might help us improve note quality, someone suggested lawyers. I noted that it had not really worked for us thus far.

Parents are often the best advocates for their children, arguably more so than older patients themselves. Without parents reviewing that information, we are likely already allowing a fair amount of inaccurate information to circulate unchecked. Not that that is an excuse, but it is an opportunity in real time during hospitalization to correct questions and inaccuracies to stop the train of misinformation. Garbage in, garbage out. It is a great opportunity to engage with families. I would also add that some AI tools now allow us to summarize notes in plain language, which will be a significant benefit for families reviewing notes, particularly those with limited health literacy.

**QUESTION:** Tell us what you're most excited about for next steps in your research?

**ANSWER:** Our tool is part of a commercial product and is already in use but has not yet been studied in an experimental way. We are really excited to run this multi-site trial to see whether it has direct impacts on patients and families. As I mentioned earlier, we are also working with Epic and Bridge to think through next steps for developing inpatient ambient solutions, including whether patients and families present during rounds may contribute to note writing and documentation. With listening devices likely becoming standard in inpatient rooms in the near future, which will open an entirely new area for investigation. We are excited about the opportunity and grateful to AHRQ for their support.