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Simplifying Clinical Notes to Reduce Provider Burden

A Conversation with Andre Quina

March 2018–MITRE's Andre Quina shares early findings from research with healthcare providers to capture high quality health data from clinical notes as part of routine care to reduce burden and improve patient care.

Q: What problem does your research address?

Quina: We're looking to solve the issue of how to effectively represent and collect the data that results from routine care of cancer patients to support clinical oncology research. Today, data isn't typically available in a form that allows researchers to aggregate it and use it in analytics. That's because most of the data that gets entered into electronic health record systems ends up in the clinical notes. Clinical notes are unstructured data and the primary source of information used by providers. You can put whatever information you want in a clinical note. However, it's very difficult to pull the data back out and use it for secondary purposes, such as in analytics and for clinical research.

The system used today for data collection involves asking providers to fill out forms using some subset of data from their clinical notes. But this process can be cumbersome and time consuming. We want to design a methodology for collecting data that works within the existing clinical workflows, won't add to the provider's burden, and produces high quality data to support secondary uses.

Q: What critical issues are you trying to solve?

Quina: There are three key issues here. Number one is determining what type of information to collect to provide the full story of the patient. The data should reflect everything required for effective care and it should come from all the specialists, organizations, and care teams engaged in the patient's treatment. The second issue is how to represent this information in a way that is consistent across organizations and technologies. This standardization is critical for exchanging data and for aggregating it into a coherent record of patient care. The third issue is how to collect this information at the point of care using existing workflows, and in a way that's low burden to the providers. Our research is working toward all three of these issues.

Q: How do the results of your research complement electronic health record systems?

Quina: MITRE is not looking to build a product that competes with an electronic health record system. We're looking to define an approach for a way to collect data that's better than what is traditionally used. We want to work directly with vendors in the industry to help them understand what we've done, show them what we've been able to demonstrate, and see if they can integrate these approaches into their systems for distribution into the broader healthcare ecosystem.

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Q: Why is your research focused on cancer?

Quina: We're focusing on cancer, and metastatic breast cancer in particular, because the need for data to support precision medicine for cancer patients is enormous. Only three percent of patients with cancer are enrolled in clinical trials. Data from clinical trials is extremely high quality, but clinical trials are costly and time consuming. Because such a small percentage of cancer patients are enrolled, there is a very limited amount of high-quality data to use to further research into the disease.

Q: What is MITRE's history of working in health data?

Quina: MITRE has been involved in health data standards and interoperability for over ten years now, working with our federal sponsors to effectively exchange—and represent—data from one provider organization to another. We've leveraged our earlier work in other domains, such as defense, and explored the technologies that drive the web to apply these lessons learned to develop more modern standards and support interoperability to improve the healthcare ecosystem. We work effectively in this space because we are chartered to work in the public interest. We are conflict free and we can bring together a coalition of organizations—from industry to clinical research and clinical care—that would otherwise find it challenging to work together. We are able to apply technology, science, and research to problems that appear extremely difficult, if not impossible, to resolve.

Q: What are the first practical steps in your research?

Quina: We're looking to define the critical information that should be collected for metastatic breast cancer patients. To demonstrate the initial proof of concept for our approach, we're targeting two of the key elements for developing new therapies—safety and efficacy. We're working directly with an active clinical trial to co-enroll its patients into our study, and we'll be calculating the same endpoints that the clinical trial is targeting: the toxicities associated with treatment, which indicates safety, and the progression of the disease, which indicates the treatment efficacy. This way, we'll be able to see how closely our approach comes to meeting the same endpoints as the clinical trial.

Q: Who are you working with to secure real-world data?

Quina: We are working with several clinical organizations including the Alliance for Clinical Trials in Oncology, Dana-Farber Cancer Institute, and Brigham and Women's Hospital. We are also working with their oncologists to understand the types of information that needs to be collected to both support patient care and support the use of analytics.

Q: How do you plan on getting around the problem of pulling data out of clinical notes?

Quina: We are going to take a page from social media. We're looking to design structured lightweight data tags, similar to hashtags, that can be entered into the clinical notes to pull out information, so the

clinician only has to enter the data once. We'll test this system for compatibility with existing electronic health record systems, and we'll test it in six clinical settings to be sure we see a variety of workflows.

Q: What's the near-term outcome?

Quina: We are looking to address all three issues I mentioned earlier—what type of data to collect, how to represent that data in standard form, and how to collect that data—in the area of metastatic breast cancer. For a patient with this disease, we are determining what information is needed by the oncologist to make decisions about patient care and what information is needed to support secondary use and research in cancer care. Then, we want to determine a way to represent that data effectively and consistently so it can be exchanged and aggregated into a single record using existing technologies. And finally, we want to determine how we can effectively collect this information at the point of care, which we'll do in conjunction with a clinical trial. We'll evaluate the collection of a subset of information that relates to safety and efficacy in disease progression and see how our data compares to the clinical results.

Q: And in the long term?

Quina: Over the longer term, we're looking at building technologies to integrate into electronic health record systems so that this approach can be scaled across a broader set of data. We want to expand into other forms of cancers and into rare diseases, like Merkel cell carcinoma and sarcomas, where this approach could have a huge impact. What we're really targeting is a repeatable approach using breast cancer as a starting point.

Q: Will this work ultimately have an impact on patients?

Quina: Absolutely, because we are hoping to significantly increase the amount of high-quality data needed to support the development of new therapies and inform new standards of care. Today, the data set that's available is limited to the three percent of patients enrolled in clinical trials. We want to open that up to one hundred percent of the patients being treated for cancer. The approach we're designing could help inform treatment decisions for every cancer patient.

Q: Is this work relevant to federal missions?

Quina: Our work helps determine safety and efficacy in the real world. That's important to an organization like CMS (the Centers for Medicare & Medicaid Services), which pays for so many therapies, and it's important to the FDA (the U.S. Food and Drug Administration), which is monitoring these drugs. It's also important to organizations like the Department of Veterans Affairs and DOD (Department of Defense) Health, which are providers themselves, working with electronic health record systems. Our work in modernizing the way that data is collected across industries and provider organizations should help federal providers provide the best care both for active military and veterans.

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Q: Will this work reduce the burden on providers?

Quina: We want to design ways to collect data that don't get in the way of providers, and that help reduce their administrative burden, giving them more time to spend taking care of their patients. Traditionally, data collection systems are inserted into provider workflows, often in the form of pop ups that don't allow the provider to proceed until they enter the information requested. Providers hate these systems. And while this approach forces data collection, it doesn't lead to high-quality data. We're working directly with providers at a number of sites to see how we can integrate our approaches into their existing workflows in a way that is useful for them, but also results in high-quality data.

Q: What's MITRE's vantage point on this problem?

Quina: MITRE's unique in that we're not bringing in an existing technology to solve it. We're starting from the ground up, talking to the providers who care for patients, and the researchers who support analytics. We're bringing our broad and diverse range of capabilities in science, engineering, and technology to design a system that's targeted to solving the problem, rather than targeted to using an existing capability that is already in place.

Q: How can others help?

Quina: We want to bring together different organizations with diverse perspectives to fully address and understand this problem. We're also looking for different clinical sites, at both large and small organizations, to enroll into our studies. We're starting with six sites this year, but next year, we want to add more clinical sites and organizations to start working in other diseases. There's a real opportunity for these groups to get involved. We also want to reach out to vendors of electronic health record systems to test our new methodologies and provide input.

Andre Quina

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Andre Quina, M.S., is an expert in the development of open-source tools for healthcare. He is leading an initiative to define a U.S. national standard for the logical content for electronic health records (EHRs). Mr. Quina has led and supported the development tools for electronic clinical quality measurement. He earned a B.S. in computer science from Worcester Polytechnic Institute and an M.S. in computer science from Tufts University.