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Commentary

Localizing Data to Expand Community Participation in Clinical Trials

By Robert Winn, MD

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Commentary Overview

- Attracting more people to cancer clinical trials requires deep understanding of communities, but traditional approaches to community engagement are falling short.
- Connecting with cancer center catchment areas is no longer a one-way street, running from the institution to the community. Instead, it requires long-lasting infrastructure building, attention to sustainability, and back and forth engagement.
- Utilizing both big and small data can foster partnerships with local hospitals, political leaders, and others who can help reach people in their communities.

Despite decades of initiatives to boost clinical trial enrollment, fewer than 1 in 20 adult patients with cancer participate in a clinical trial. And the news is worse for racial and ethnic minorities. A 2018 study showed a *decline* in clinical trial participation by racial/ethnic minorities over a 14-year span. Attracting more people to clinical trials requires deep understanding of communities, but traditional approaches to community engagement are falling short.

In recent years cancer centers and researchers have reassessed their connections to their catchment areas. It’s no longer a one-way street, running from the institution to the community; instead, there’s "bi-directionality." We listen for the voice of the community. In an era emphasizing technology, Big Data, and the individual—even down to the cellular level—what we’re missing is communities. Adding that component will help us not only to deliver better clinical care, it will help us deliver more people to clinical trials.

Building Community Infrastructure

We have population scientists, clinical specialists, clinical trialists—call them "super specialists"—who have gone into the community and developed brilliant ideas and opened studies but have found, over time, that many of their efforts were episodic, unsustainable events.

Fortunately, we've gotten smarter over the years, learning that we need something more like the Army Corps of Engineers rather than the Special Forces. Something that would be in the community, long-lasting, building infrastructure, thinking about sustainability, and engaging back and forth.

Extending the military metaphor, since the days of Bunker Hill, Gettysburg, and other transformational conflicts, the way you really win a battle is with your reconnaissance team. A group of people who can get important information from the community and analyze it in a way that informs both the scientist and the community about where they should be in relation to each other.

During my tenure as director of the University of Illinois Cancer Center (2015-2019), we deployed an information science team into our catchment area to gather and analyze GIS data, geospatial mapping, traditional cancer epidemiology, direct acyclic graphing, and other measures.

In a **2018 JAMA Oncology paper**, we examined lung cancer screening in the inner city. A widely cited study, the National Lung Screening Trial, looked at a small sample of African Americans (4.5 percent of study participants). Zeroing in on Chicago neighborhoods with large minority populations, nearly 70 percent of our study's subjects were African American. We found evidence that a more detailed assessment of individual risk of lung cancer may be more effective than focusing only on age and smoking status criteria. We also found that screening that is skewed toward the white population could paradoxically increase racial disparities in lung cancer outcomes.

Small Data, Big Impact

Another example: We had five counties in our catchment area; two urban and three fairly rural. We could have stopped there and said, "We've defined our catchment area." But what if you had a catchment area that really motivated you to identify hotspots, where to focus your resources, and perhaps partner with other cancer centers?

We discovered that we had not only prostate, lung, and breast cancer in the catchment area, but cervical cancer kept showing up as well, in both urban and rural areas. Cervical cancer should be eradicated; it's highly preventable. But we found an area that had two times the death rate from cervical cancer compared to the rest of the country.

As a result, we started working with the Illinois Department of Public Health, trying not only to increase Pap smears within our federally qualified health centers, then hopefully across the city and state, but also introducing the concept of self-swabbing, which is happening in Latin America, parts of Africa, and New Zealand, where women have much more acceptance of the practice. With the new technology and point-of-testing services, we believe we can find out sooner about cervical cancer than with the standard Pap smear. The inspiration for that innovative screening came directly from reaching into communities and understanding our catchment area, pursuing not just the science that we were curious about, but the science that the community needed.

Sometimes Big Data hides some very important issues. For instance, life expectancy in Cook County overall resembles the rest of the country, but within certain neighborhoods the picture changes dramatically. We're in an era of precision health and precision care. By having big *and* small data, we can have focused, targeted programs in partnership with community hospitals and political leaders who can help us reach people in those communities, helping them feel less afraid and more motivated to participate in clinical trials.

That played out in our shift from zip codes to political wards as a parameter for collecting and analyzing data. If someone says, "I'm from the 19th Ward," that's a significant identifier; people understand what that means. Consequently, when talking to a local political leader, I would show them that prostate cancer is two times more likely in their ward than in the country. That changed our conversation. They would ask, "How can I help?" and they would be more willing to carry our message and motivate their constituents.

From Illinois to Virginia

In my role as director of the VCU Massey Cancer Center, in Richmond, Virginia, I hope to implement the innovative methods of community outreach that we developed at Illinois. Beyond VCU's world class basic science research, I will also focus on expanding its health equity, population health, Big Data, and implementation sciences. More clinical trials of all types—Phase I, prevention, non-treatment, and interventional—are also in the cards.

In addition, we will be aggressively recruiting physician-scientists and researchers focused on survivorship, and, as in Illinois, we will build an innovative catchment area research team that will optimize the impact that our work has on the community. I also hope to build on the success of established VCU researchers like Dr. Steven Woolf, who has developed "usable" community data showing that the zip code you live in greatly affects your health.

If loving science is wrong, I don't want to be right. I believe in the power of single cell assays, machine learning, and all of the other science, but I also believe that democratization of data and deep community engagement are just as important. In the light of our progress, we cannot let our communities be invisible.

A portion of this AACI Commentary *is excerpted from Dr. Winn's presentation during a panel discussion on innovative ways to enroll patients from diverse backgrounds to clinical trials, at AACI's 11th Annual Clinical Research Innovation (CRI) Meeting, July 9-11, 2019, in Chicago.*

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