

The Avoca Quality Consortium  
**Leading Change  
Collaborative Forum**

## Avoca Quality Consortium® Leading Change Collaborative Forum

### Meeting Highlights

**Topic: Patient Engagement Trends and Solutions**

**Meeting Date: February 16, 2021**

### Background Information

With the emergence of the COVID-19 pandemic, the importance of structuring clinical trials that are patient-centric has become a top priority for improving the outcomes and value of the studies being conducted, and to reduce market access barriers. A key component for conducting clinical trials that are patient-centric is to engage the patient by giving them a voice in the process. Patient engagement along with adopting new technologies that reduce or remove barriers and ease the patient burden through simplification, while continuing to ensure patient safety and regulatory compliance, will improve patient recruitment and retention and ultimately the patient experience. As COVID-19 continues to pose a challenge to the industry, the focus on patient centricity is likely to continue.

### Discussion Summary

**What should best practices as it relates to the patient experience look like?**

- In the clinical research industry, companies are working increasingly hard to incorporate the patient perspective into studies, yet it is insufficient to think about “the patient” as a blanket solution for a wide population involved in a clinical trial. Different factors affect patients’ participation and success in a trial, such as race, access to care, mobility issues, negative perceptions of clinical research, and more.
- Diversity in clinical trials is very important. We need to incorporate the voice of the patient in every single trial.
- Patient populations should be considered early in the process, ideally prior to the development of the protocol. Flexible protocols should be considered, to accommodate patient differences.
- It is challenging to use ClinicalTrials.gov. This remains one of the significant issues both for patients and physicians seeking solutions. It also affects recruiting within the industry. Some organizations are working toward improvement.
- An element of participating in a clinical trial is the likelihood of receiving a higher level of care. One panelist contrasted the level of care she received as a COVID trial participant who actually contracted the virus versus other family members who also contracted the virus. Her care was far superior to that of other family members, one being much more ill than she was with COVID-19.

- Clinical research is a positive care option and should be communicated as such, not just for emergencies or in life-or-death situations.
- Connecting patients to physicians at the right time is important. We need physicians to have a better experience. They also need to have an understanding of how to get connected with clinical trials. Providers should be considered in the study workflow.

### **What are the most promising services impacting the patient experience?**

- Understanding technology and having fit-for-patient options.
- There are so many platforms. This can be a challenge to patients.
- Messaging is a problem. Many people think clinical trials are a last resort. The industry needs to make patients comfortable, feel safe, secure, and empowered.
- New technologies to seek and find clinical trials could make a positive impact.
- Human connectivity – feeling safe through interaction with healthcare and patient networks.

### **How do we build trust?**

- Reach out to communities that are most distrustful and provide information in a two-way conversation on an ongoing basis.
- Working with patient advocacy groups is important. Take time to listen and deliver on what you say you will do. Treat all patients well.
- Recognize that patient networks will communicate with each other.
- Conduct a mid-trial survey to see how things are going and fix the things that are not going well. Do the same thing at the end of the trial and adjust for the next phase.
- Trust has to start before people are sick; build relationships within the community.

### **Costs of patient engagement programs can be high:**

- In order to manage costs, there needs to be a definitive construct in terms of endpoints. If what we are doing now can consolidate technologies in the future, it may be a worthwhile investment.
- COVID has forced the industry to look at whether or not there is a need to collect more data than is absolutely necessary as it pertains to the trial.
- If your study is able to enroll quickly, there could be a significant rate of return.
- Need to define what are “need-to-haves” and what are “nice-to-haves”.

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*If you are interested in learning more about the [Avoca Quality Consortium \(AQC\)](#) or its *Leading Change* series, please contact [Dawn.Auerbach@theavocagroup.com](mailto:Dawn.Auerbach@theavocagroup.com).*