

It's Current

Epilepsy Resources and Updates



Taking the “Pulse” of Our Society with Q-PULSE

Jacqueline A. French, MD

NYU Comprehensive Epilepsy Center, New York, NY, USA

Correspondence: Jacqueline A. French, MD, Professor, NYU Comprehensive Epilepsy Center, 223 E. 34th St, New York, NY, 10016, USA

Jacqueline.french@nyumc.org

Have you ever been in clinic, seeing a patient with a unique situation that perplexed you, and wondered what other epilepsy specialists would do in the same situation? Perhaps you go to the literature, hoping to find some guidance, and realize there is nothing helpful or relevant. In fact, perhaps this relates to a scenario that does not lend itself to a clinical trial. How often do you ask a colleague about the case because you really want another opinion? I know this often happens to me.

This is one of the motivations for creating a novel mechanism—Q-PULSE—being rolled out at AES this year. We have asked 200 epileptologists, carefully chosen to be representative of our clinical colleagues (in terms of geography, specialization, pediatric and adult, gender, etc.) to be “on call” to answer questions that would be of general interest. The initiative, called Q-PULSE, stands for the “Quantitative Practical Use-Driven Learning Survey in Epilepsy”. This is a mouthful, but the short version says it all: This is a survey that takes the “pulse” of our community. You will see Q-PULSE popping up in a number of different forms over the coming months. The questions and answers will be posted on the new (and improved) AES website coming next year. The results may be shown as part of an AES lecture. They will be presented here in *Epilepsy Currents*, and may be accompanied by a majority/minority debate.

We are happy to present the first Q-PULSE survey results. For the first question, we wanted to ask something that has been on many people’s minds but for which it is difficult to get an answer: Is epilepsy surgery changing over time? Many feel that as surgery has evolved over the last 20 years, it is moving away from temporal lobe epilepsy and more toward complicated nonlesional cases. We were curious about whether this was a widely perceived phenomenon. The beauty of asking through a mechanism such as Q-PULSE—rather than, say, through raising of hands at a meeting—is that everyone answers from their own computer, so we can avoid “crowd-think”. Q-PULSE is completely anonymous. We know who the panel is, but no one knows how each individual answers the questions. Yet, since we have asked each of them to fill out a demographic questionnaire, we can go back and find out how all the

pediatric versus adult epileptologists answered, how those in private versus academic centers answered, and so on.

It is important to remember that the Q-PULSE responses are not meant to replace scientific evidence and do not necessarily reflect the “truth”. The mechanism must be used wisely. It is likely that answers to the same question may even change over time, as new information or new practices emerge. What, then, can be learned? We believe that for some questions, it would be important to know if there is strong unanimity of thought in the epilepsy community; for example, if we asked, “Would you initiate valproic acid in a woman of childbearing age with idiopathic generalized epilepsy as a first AED?” we might expect that the vast majority of respondents, if not 100%, would say “no”. This unanimity of thought might be useful to present to general neurologists, who are not as informed on the topic. On the other hand, there may be questions for which the response is divided evenly; for example, if one asked, “Would you switch a woman off Depakote in the 3rd trimester if her seizures were well controlled?” the response might vary significantly. In this case, someone from each point of view might be asked to volunteer a commentary supporting his or her beliefs. Moreover, Q-PULSE could be used to poll the community prior to initiating a large randomized trial to see if there is equipoise for randomization. For example, the Radiosurgery or Open Surgery for Epilepsy (ROSE) trial—a large, expensive NINDS-supported trial—recently was shut down for lack of recruitment. If prior to initiating the trial, a Q-PULSE poll had asked physicians whether they would be willing to randomize patients to gamma knife versus temporal lobectomy, they might have found out that the answer for many physicians was “no”.

Who writes the questions? At present, the Q-PULSE committee does, with input from other AES committees and the Q-PULSE panel physicians (who have been told that their questions will be prioritized). However, anyone can submit a “burning” question to the committee for consideration.

We would like this mechanism to be a living part of the AES. So, we invite *Epilepsy Currents* readers to look at these first results and think about how Q-PULSE could be used in the future. One concept under consideration is taking a page from the popular online press and asking people to answer the Q-PULSE question online—with the incentive that if they do, they will get to see how everyone else voted.

Hopefully, this will be the first of many Q-PULSE polls to be published in *Epilepsy Currents*.