

SWOG's "Ten Key Questions Investigators Can Ask Their Patient Advocate"

For the Design stage, we believe that five questions are most critical. Please ask for our input on these questions at the Design stage:

1. *How important are the goals of this trial to the patient community and why?*
2. *What patient-reported outcomes should be added as objectives?*
3. *What suggestions do you have to address issues that might make patients hesitant to enroll?*
These issues could include use of placebo, randomization, access to therapy off-label, side effects, treatment logistics, follow-up and surveillance, financial burden, etc.
4. *What other therapies or competing trials might keep patients from participating in this trial?*

And finally,

5. *What benefits will this trial bring to patients in the immediate and long term?*

At the Develop stage, the trial is subject to a great deal more rigor, with details being resolved operationally, strategically, and tactically. The questions, then, are more focused:

1. *What concerns, if any, do you have with the eligibility criteria?*
These might include co-morbidities and underserved populations.
2. *How can the informed consent package and other patient literature be improved so that the information is conveyed in simple, patient-friendly language?*
3. *What unanswered questions or areas of concern or confusion do we need to address with additional patient communication?*

And finally,

4. *What barriers or issues do you see with regard to collection and banking of blood and/or tissue specimens for future research?*

In the Deliver stage, plans are being executed and adjusted based on results. This would include the protocol and, of course, the accrual plan. Ask your Patient Advocate this question during the Deliver stage:

1. *How can your advocacy group and other organizations increase awareness about this trial?*

Options may include newsletters, website listings, blog entries, meetings, community outreach, etc.

Awareness of trial results is also important, so a plan to communicate the results of completed trials should also be discussed.