

Survey Feedback on PROs in SWOG Trials: Peer-to-peer Feedback

123 responses were received from a survey distributed to the Lead ORPs and the ORP listserv prior to the September 2026 Patient-Reported Outcomes webinar. Many respondents shared how they handle different aspects of administering PROs and patient interactions around PROs. This is a summary of their feedback.

When do you administer PROs in relation to the study visit?

- Prior to the clinical visit, while the participant is fresh
- During the clinical visit
- During chair time (during infusion)
- After the clinical visit
- Participant completes at home and mails back

How do you manage PRO administration?

- Remind the participant prior to the visit
- Print out paper PROs prior to visit and bring to participant at clinical visit
- Be unobtrusively present/nearby while participant completes PROs, to be available to answer questions
- Make sure there is time to complete PROs at the visit
- Review the PROs with the participant during the visit
- If symptoms are an issue:
 - o Another person may read the questions aloud and mark the participant's responses
 - o Provide thicker pens for participants with neuropathy

How do you communicate with the participant about PROs?

- Review PROs at time of consent
- Be sympathetic as to quantity (number of pages) and duration (how long it will take to complete the questionnaires)
- Give appropriate expectations at start (how long the questionnaires are, specific sensitive topics they will encounter)
- Thank participant when they finish their PROs and let them know that their answers help us choose new treatment plans or guide cancer care for future patients
- Inform patients that how they feel is just as important as the treatment itself

Helpful things to share with the participant:

- "Your opinion matters"
- "How your quality of life changes throughout the study and in comparison to the different arms can make the difference whether a study agent or treatment gets approved"
- "Patients often tell me that they feel vulnerable and that they've lost all control of their health and lives- I make sure they understand that this is their moment to shine! I tell them that the study group wants to hear how they feel physically and emotionally."

