

## Module 10 – Quality of Life Research

### Summary of Key Points

This concludes Module 10: Quality of Life Research. Before you take the quiz, let's review some key points.

- Quality-of-life research can study a broad range of ways to improve the well-being of people living with SCI.
- One of the things that is unique about quality-of-life research is that it can examine a study participant's own perceptions of how they live and how they feel.
- The endpoints in studies that measure the participant's own perceptions are called self-reported outcomes, or PROs (which stands for patient-reported outcomes).
- PROs developed for the general population may not be relevant to or appropriate for people with SCIs.
- New PROs must be rigorously developed and tested because they measure things that are subjective – such as how someone feels or what they think – and because they are subject to interpretation by the people who fill them out.
- Research advocates can be instrumental in ensuring the utility, reliability, and validity of PROs by:
  - Helping to design PROs
  - Helping to design research studies to test a PRO's reliability and validity
  - Advising on who from the community should be included in tests of a PRO, and
  - Interpreting the results of the research testing a PRO.