PATIENT REPORTED OUTCOMES RESEARCH IN A REAL TIME PRACTICE NETWORK

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OBJECTIVES: To examine logistics and feasibility of conducting Patient-Reported Outcomes (PRO) research in a real-time practice network. METHODS: To conduct a Summer 2007 methodological pilot study of the psychometric development of Nutrition Quality of Life (NQOL—a PRO survey), the 600 registered dietitians (RDs) of the Dietetics Practice Based Research Network of the American Dietetic Association were contacted though the network’s coordinating center. If RDs had outpatient, adult, dietetics practices, they were invited to participate and asked to meet study site criteria: obtain approval of supervisor, determine availability of Institutional Review Board (IRB) office to perform June 2007 review, and attend 1.5-day training session. Between July 1–24, RDs asked patients presenting for 1st or 2nd medical nutrition therapy (MNT) visits to participate. During that visit, RDs collected informed consents/demographics and conducted their MNT session; patients completed the 50-item NQOL prior to the session. For reliability studies, 50% of the enrollees were asked to complete a 2nd NQOL two days before the next visit; immediately before that MNT session, they were asked to complete a 3rd administration in the office. Weekly telephone focus groups were conducted with RDs to monitor pilot’s progress and obtain qualitative evaluations. RESULTS: 40 RDs expressed interest and met criteria; 10 from geographically/ethnically diverse sites were selected and attended the training. Four IRB approvals were delayed limiting enrollment. Overall 86 patients (range: 3–18/site) were enrolled with 12 refusals; only 58% of enrollees had a return visit. Of 49 patients in the test/retest arm, 53% completed the reliability protocol. RDs indicated that they would have to modify patient’s initial visit logistics to accommodate informed consent processes. CONCLUSIONS: PRO research is feasible in a real-time practice network; however, three pressure points were identified: lead time for IRB approval, time for informed consent, and low MNT return visit rate.