

# Measuring Patients' Health-Related Quality of Life: Practical Considerations For Implementing an Outcomes Management Program

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**ABSTRACT** There are many ways to capture health-related quality of life as part of an outcomes management program. One of the most commonly used methods is through patient self-administered questionnaires such as the Short Form-36 (SF-36). There are different methods for administering and analyzing the SF-36. This article illustrates some of the factors that health care institu-

tions and pharmacists need to consider before an outcomes management program using the SF-36 can be implemented. The choice of which system to use is dependent on the site personnel availability, access to equipment, how fast the data is needed, the acceptable level of data error, and the SF-36 questionnaire volume per site per day.

**W**ith the release of the Institute of Medicine's report, *To Err Is Human: Building a Safer Health System*, the quality of our health care system has been at the center of the nation's attention.<sup>1</sup> The quality of health care has traditionally been measured by evaluating the structure and processes of the health care system. However, with the renewed awareness that patient outcome is the ultimate measure of quality, there has been a fundamental shift towards concentrating quality improvement efforts on patient-focused outcomes.

Accrediting organizations for health care providers—including the Joint Commission on Accreditation of Health Organizations and the National Committee for Quality Assurance—are increasingly interested in the measurement and documentation of patient-focused outcomes. Purchasers of health care services—including state and federal governments, insurers, and employers—are starting to concentrate on measuring important patient-focused outcomes such as health-related quality of life (HRQoL). For some chronic conditions, such as migraine or depression, HRQoL can be an important indicator of health care quality.

Because of this fundamental shift, hospitals and pharmacists are beginning to collect and capture patients' HRQoL as part of outcomes management programs. One of the most commonly used methods for capturing HRQoL is through self-administered questionnaires such as the Short Form-8 (SF-8), Short Form-12 (SF-12), or Short Form-36 (SF-36).<sup>2</sup> The New England Medical Center has implemented outcomes management programs, assessing HRQoL via the SF-36, as part of routine clinical practice.<sup>3,4</sup> In summary, patients complete an optically scannable SF-36 during

hemodialysis treatment, peritoneal dialysis clinic, or nephrology clinic visits. Completed questionnaires are reviewed by staff for errors and then scored for results. Within one week, a report of individual patients' responses is generated, reviewed, and placed on the patients' medical charts.<sup>3</sup> The patients' responses are compared to previous SF-36 scores and any significant changes are discussed with the patients to help determine potential reasons for the differences. In this way, the SF-36 provides clinicians with a quantitative record of patients' experience with illness as well as treatment.

The SF-36 is a widely accepted survey instrument for assessing a patient's HRQoL. The SF-36 measures HRQoL in eight domains: Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health, and it has two summary scores (Physical and Mental).<sup>5</sup> The SF-36 has demonstrated its reliability and validity in multiple populations<sup>5</sup> and can be administered in various ways. The SF-12 is an abbreviated version of the SF-36 health profile, consists of the two summary scores, and can be completed within three minutes.<sup>6</sup> The SF-8 is an eight-question survey in which each of the eight dimensions of health measured by the SF-36 is represented by a single question.<sup>7</sup> However, because of the brevity of both the SF-8 and the SF-12, they are usually embedded into longer, condition-specific surveys and not used as a single measure to capture HRQoL.<sup>6</sup>

There are four different methods for administering the SF-36. Traditionally, patients complete the questionnaire with a pencil and a scannable paper form. The completed surveys are then analyzed to generate scoring results and reports. This is the method that is used by the New England Medical Center.<sup>3</sup> This requires some expertise and specialized computer software. Three newer methods for self-administration and analysis of SF-36 questionnaires rely on faxes, computer technology, and the Internet.

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For fax-based scoring, a patient completes the SF-36 survey by the paper-and-pencil method, but the completed questionnaire is sent by fax to a vendor for analysis and scoring.<sup>9</sup> The scored results are faxed back to the practice site within minutes. For the computer-based system, touch-screen technology allows patients to view each SF-36 question on a computer screen, and then touch the computer screen with a light pen to indicate their responses. Patients' SF-36 questionnaire results are directly downloaded into a computer database. The computer touch-screen system provides SF-36 scoring results and reports them immediately, so the data are available for clinical review during the office visit.<sup>10</sup> The last method of SF-36 administration and scoring is via the Internet. For the Internet, a service is offered in which an electronic database of patients' completed SF-36 survey data can be developed, maintained, scored, and analyzed.<sup>11</sup> The service allows clinicians to collect patients' HRQoL data, monitor changes in patients' health status over time, and download results for further analysis and reporting.

With these different systems available, how does a health care organization or provider decide which system to implement to measure HRQoL as part of an outcomes management program to improve health care quality? There are various factors and issues that institutions need to consider before choosing the system that is most appropriate for them.

### ARE PERSONNEL AVAILABLE TO ADMINISTER THE SF-36?

One of the first factors that needs to be considered is whether personnel are available at the clinical site(s) to perform the tasks needed to collect, administer, and analyze surveys (Table 1). The clinical site needs to determine who can perform the additional activities to administer and collect SF-36 data, given the other duties and responsibilities of the office personnel. Various personnel, such as medical assistants, medical students, office managers, nurses, or pharmacists, might be available to perform these duties.

When choosing who will administer the SF-36, the candidate's skills, expertise, and competing responsibilities should be considered. If a site does not have personnel available, then fax, computer-based, or Internet-based systems might be preferable because these systems require less personnel time to administer, as compared to the traditional paper-and-pencil method. In addition, the technology-based methods do not require on-site experts to analyze and report the data. For example, to decrease staff burden, one health care organization switched from the traditional scannable method for SF-36 administration to the computer-based system.<sup>12</sup>

### IS THERE ACCESS TO NECESSARY EQUIPMENT?

For the traditional paper-and-pencil administration, patients complete scannable forms. An optical scanner is needed to read the surveys and report the raw questionnaire data. Therefore, the second factor that needs to be considered is whether the

Table 1 Factors That Need to be Considered

- Personnel availability
- Access to equipment
- Need for speed data
- Acceptable level of data error
- System costs and volume of questionnaires

clinical sites have access to equipment such as optical scanners. If an optical scanner is available within the organization, then the traditional paper-and-pencil approach might be appropriate. However, if a scanner is not available, then sites might need to consider fax-based scoring, computer touch-screens, or the Internet-based approach for SF-36 administration.

Although an optical scanner is not necessary for the fax, computer-based, and Internet-based approaches, other specialized equipment is still needed. The fax-based scoring approach requires a fax machine to send and receive SF-36 information, whereas the computer touch-screen method needs a computer solely dedicated to collecting, storing, analyzing, and reporting SF-36 data. In addition, the Internet-based approach needs the medical office and/or the patient to have a computer with Internet access. Therefore, the health care organization needs to consider whether this equipment is available at the practice sites in order to determine which method would be best to implement.

### WILL RESULTS BE USED AT THE TIME OF VISIT?

The third factor to consider is whether the health care organization and providers would like to have patients' SF-36 data available to review and address at the time of visit. Information obtained from SF-36 results could lead the clinician to modify patient care plans, thereby possibly improving the quality of care provided.

The traditional method requires that the questionnaires be scanned and then analyzed for results. Depending on the personnel expertise and equipment availability, it could take days to months to receive the SF-36 scoring results. If the health care organization wants patients' SF-36 results to be reviewed during the office visit, an alternative approach is needed that provides these results almost instantaneously. Fax, computer touch-screen, and the Internet methods can provide results quickly. Therefore, these methods might be more suitable for the practice sites. One health care organization was using scannable SF-36 forms for collecting patients' HRQoL, but found that it needed to have data and analyses available on demand. Therefore, the organization implemented the computer-based system for SF-36 administration.<sup>12</sup>

### WHAT IS AN ACCEPTABLE LEVEL OF DATA ERROR?

Another important factor to consider when collecting data for an outcomes management program is data error. The traditional approach can be associated with poor data quality

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**Table 2 Cost Per Survey at Different Annual SF-36 Survey Volumes**

Type of cost	Fax-based scoring method	Scanning-based scoring method	Computer touch-screen method
250 surveys (one survey/day)			
Cost per survey	\$9.62	\$29.28	\$26.20
1,000 surveys (four surveys/day)			
Cost per survey	\$5.88	\$8.34	\$6.94
1,250 surveys (five surveys/day)			
Cost per survey	\$5.63	\$6.94	\$5.65
1,500 surveys (six surveys/day)			
Cost per survey	\$5.47	\$6.01	\$4.80
2,500 surveys (10 surveys/day)			
Cost per survey	\$5.14	\$4.15	\$3.09
5,000 surveys (20 surveys/day)			
Cost per survey	\$4.89	\$2.75	\$1.80
7,500 surveys (30 surveys/day)			
Cost per survey	\$4.80	\$2.29	\$1.37

Adapted from: Lofland JH, Schaffer M, Goldfarb N. Evaluating Health-Related Quality of Life: Cost Comparison of Computerized Touch-Screen Technology and Traditional Paper Systems. *Pharmacotherapy*, November 2000; 20(11):1390-1395.

because respondents might unintentionally skip questions and provide multiple responses to single survey items.<sup>12</sup> Compared to the traditional method for SF-36 administration, the fax-based approach obviates the need for data entry, thereby potentially improving data quality. The computer touch-screen and Internet methods also eliminate additional data entry and reduce the number of missing or improperly completed items, because patients have to answer one question before advancing to the next. The computer touch-screen system or the Internet method for administration might be the best choices to minimize data error.

### HOW MUCH DOES THIS METHOD COST?

The last issue that needs to be considered is the costs associated with the various methods. Recently, a cost identification study was conducted to estimate and compare the costs of the resources needed for three different methods (traditional, fax, and computer touch-screen) of administering and analyzing the SF-36 questionnaire in a clinical practice setting.<sup>13</sup> The annual fixed, variable, and total costs per questionnaire were calculated for each of the three different approaches.

The study findings revealed that as the volume of SF-36 surveys administered rose, the total annual cost per survey decreased for all three methods of administration. The fax-based method was the least costly method for administering four (or fewer) SF-36 surveys per day as part of an outcomes management program. However, as the volume of administered SF-36 surveys increased to six surveys per day, the least costly method was the computer touch-screen approach (Table 2).<sup>13</sup>

Internet-based administration of the SF-36 was not available when the cost identification study was conducted; therefore, the costs of the Internet-based methodology were not evaluated in that study. Internet services are now available in which electronic

databases of completed SF-36 surveys can be developed, maintained, scored, and analyzed for a flat fee with an additional fee for each completed survey contained within the database, with a minimum of 500 surveys completed.<sup>11</sup> Health care organizations and providers need to determine the volume of SF-36 surveys they anticipate administering and then compare the cost of Internet-based administration to the three other methods for administering the SF-36 to determine the system that would be most appropriate for their practice sites.

### CONCLUSION

For those pharmacists and P&T committees looking to begin an

outcomes management program measuring HRQoL using the SF-36 in their practice settings, this article illustrates some of the practical factors that first need to be considered. The choice of which system to use for administering the SF-36 is dependent on the site personnel availability, access to equipment, the speed with which data is needed, the acceptable level of data error, and the SF-36 questionnaire volume per site per day. ■

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