

## Advance Registration Form

Name \_\_\_\_\_ Highest Degree \_\_\_\_\_  
Title \_\_\_\_\_  
Organization/University \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_ Country \_\_\_\_\_  
Phone \_\_\_\_\_ Fax \_\_\_\_\_ Email \_\_\_\_\_

### Please circle those that apply:

Which track do you plan to attend?      Track I      OR      Track II  
If attending one day, which day?      Monday      OR      Tuesday

\*Best savings

### Please check one payment that applies:

	One day course	Two day course
Received By January 5:	\$ 595.00 <input type="checkbox"/>	\$ 995.00 <input type="checkbox"/> *
Received After January 5:	\$ 615.00 <input type="checkbox"/>	\$ 1,015.00 <input type="checkbox"/>

Each meeting registration includes continental breakfast, lunch, and breaks each day; along with a one-hour cocktail reception on Monday evening!

### Reduced Fees for ISOQOL Members!

ISOQOL members may subtract \$50 off their registration fee for the two day course, and \$20 for the one day course. If you are not a current ISOQOL member, join now to take advantage of this special offer. Membership categories/fees are as follows:

YES! I want to join ISOQOL. Enclosed is payment in the amount of \$ \_\_\_\_\_ for membership.

Regular member = \$75.00; Contributing member = \$200.00; Student/Retired = \$30.00

#### PAYMENT:

Please check the desired payment method (make checks payable to ISOQOL in US dollars):

Check       Money Order       Credit Card

Total payment in US dollars \_\_\_\_\_

Visa or Mastercard Number \_\_\_\_\_ Exp. \_\_\_\_\_

Signature \_\_\_\_\_

Please return form and payment to: ISOQOL, 6728 Old McLean Village Drive, McLean, VA 22101  
OR you may FAX to 703-556-8729 if paying by credit card. Please do NOT fax and mail to avoid duplicates. You will receive confirmation in writing via email.

\* This form may be reproduced. Share it with a colleague!

**International Society for Quality of Life Research**  
6728 Old McLean Village Drive, McLean, VA 22101-3906  
(703) 556-9222 \* Fax (703) 556-8729  
info@ISOQOL.org \* www.ISOQOL.org



## International Society for Quality of Life Research (ISOQOL)

# Methods Workshops

Offering Two Tracks

February 5-6, 2001

Hotel Washington

(Pennsylvania Avenue & 15th Street, NW)

Washington, DC

Preliminary Program and Registration Form

### WHO SHOULD ATTEND?

- social and medical scientists
- government, industry and academic health care researchers
- managed care administrators
- health care consultants
- third-party payers
- policymakers
- statisticians

### **Track II, Workshop 3 (Tuesday, 9am-12pm)**

#### **Analysis of longitudinal studies with missing HRQOL data**

*Diane L. Fairclough, DrPH, AMC Cancer Research Center, Denver, CO*

In this session, we examine the most widely used methods of longitudinal data analysis and how they are effected by different types of missing HRQOL data. The objective is to go beyond learning the definitions of Missing Completely at Random (MCAR), Missing at Random (MAR) and non-ignorable or Not Missing at Random (NMAR) and to understand how different types of missing data influence the results obtained from these analytic techniques. Methods to be examined include repeated t-test, change from baseline, baseline as a covariate, mixed effects and repeated measures models for incomplete data. We also discuss how joint estimation of QOL measures and other clinical outcomes may be used to convert a NMAR problem to MAR. Participants should have some experience with the analysis of multivariate analysis: longitudinal data, repeated measures or MANOVA.

### **Track II, Workshop 4 (Tuesday, 2pm-5pm)**

#### **Imputation for non-randomly missing HRQOL data in longitudinal studies**

*Diane L. Fairclough, DrPH, AMC Cancer Research Center, Denver, CO*

This session examines methods of imputation for longitudinal studies when the missing HRQOL assessments that are believed to be non-ignorable. Simple imputation methods are briefly discussed but the focus is on multiple imputation methods such as Approximate Bayesian Bootstrap (ABB), explicit models, 'closest predictor' and delta-adjustment. We discuss the strengths and weaknesses of these methods in longitudinal studies with non-ignorable (NMAR) missing data. The workshop includes hands-on experience with selected techniques (participants are encouraged to bring a hand calculator). Participants should have some experience with the theory and analysis of multivariate analysis: longitudinal data, repeated measures or MANOVA.

## **TRACK I**

Four hands-on workshops are offered during this two-day block. Each workshop will last for three hours. Participants may register for and attend only one day if desired. This track begins at 9:00 a.m. on Monday, February 5 and ends at 5:00 p.m. on Tuesday, February 6. Registration fees include two continental breakfasts, two lunches and one reception. Refer to the registration form for more details.

**An overview of Track I: "Topics in Quality of Life Instrument Development and Validation"**  
These methods workshops provide "hands-on" training experience in intermediate methods for conceptualization, development, and validation of self-report-based quality of life data. Participants will learn the principles and techniques of psychometric validation methods. The 2-day workshops are designed for quality of life researchers with a basic understanding of psychometric methods who seek further training in the purpose and application of state of the art techniques for QOL instrument selection, development and validation. Topics include development of measurement models, cognitive interviewing, questionnaire development, differentiating HRQL generic and specific questionnaires and profile and preference measures, and discussion of the field of psychometrics and related topics.

### **Track I, Workshop 1 (Monday, 9am-12pm)**

#### **Neglected aspects of HRQL questionnaire development**

*Sheri E. Fehnel, Psychometrician, RTI Health Solutions, Research Triangle Institute, Research Triangle Park, North Carolina*

In recent years there have been major advances in methods for gathering questionnaire content designed to assess subjective health status, for example, the use of face-to-face interviews with representatives of patient and focus groups. However, there has been a decline in the amount of attention paid to the more detailed aspects of questionnaire design such as instructions to respondents, format, layout, and wording of items and interpretation of items by different groups. Also, the choice of "user friendly" response options seems to be a topic which is seldom discussed. These issues can have profound effects on responses and missing data. The emphasis of this session is on ensuring "respondent friendliness" of questionnaires. The participants will be asked to complete several existing questionnaires; findings will be discussed.

### **Track I, Workshop 2 (Monday, 2pm-5pm)**

#### **Disease-specific and generic HRQL instruments: practical considerations**

*William Holmes, MD, University of Pennsylvania School of Medicine and Philadelphia Veteran Affairs Medical Center, Philadelphia, PA and Rick Berzon, DrPH, Boehringer Ingelheim Pharmaceuticals, Ridgefield, CT*

In this session, we examine approaches to selection of existing and development of new HRQL instruments. Selection of generic or specific questionnaires and of profile or summary-score and preference measures depends upon the research question, study design, and setting under consideration; and of the audience for whom the work is intended. Development of new instruments requires time, skill, an understanding of the likely use and context of the final product, and an adequate budget. Discussions emphasize practical considerations within clinical research. The workshop leaders present examples from their own work in HIV/AIDS and detail strengths and limitations of several of the most frequently used HIV-specific HRQL instruments.

### **Track I, Workshop 3 (Tuesday, 9am-12pm)**

#### **An overview of psychometrics in quality of life research: what is it and when do I need it?**

*Jane Scott-Lennox, PhD, Piedmont Research Institute, Inc., Chapel Hill, NC*

Many experienced researchers interested in quality of life research first encounter the term “psychometrics” when they begin to use patient questionnaires in their QOL studies. Despite the long history of psychometric evaluation, there are few texts available to describe psychometrics and why and in what circumstances these tools are needed. This session provides an overview of psychometric evaluation for clinical researchers and data analysts who need to evaluate the psychometric properties of questionnaires. Questions addressed include: What is psychometrics? Why and when are psychometric evaluations needed? What are the critical psychometric tests for evaluating research instruments or clinical assessments? How good is good enough when it comes to psychometric properties? How and where can I learn more about psychometrics?

### **Track I, Workshop 4 (Tuesday, 2pm-5pm)**

#### **Cognitive approaches to HRQL assessment**

*Ivan Barofsky, PhD, The Johns Hopkins University, Baltimore, MD*

We begin this session by reviewing available literature on Cognitive Aspects of Survey Methodology (CASM) and continue with case illustrations of how cognitive science is used in the development and refinement of HRQL assessment. Included in this session is a discussion of the role of implicit cognitive theories in formulating personal histories and how these theories can assist researchers evaluate existing and develop new self-report instruments. Also to be discussed is the relationship between culture and cognition and how this interplay may affect HRQL assessments across cultures; and the cognitive rules that are involved in producing summary measures.

## **TRACK II**

Four hands-on workshops are offered during this two-day block. Each workshop will last for three hours. Participants may register for and attend only one day if desired. This track begins at 9:00 a.m. on Monday, February 5 and ends at 5:00 p.m. on Tuesday, February 6. Registration fees include two continental breakfasts, two lunches and one reception. Refer to the registration form for more details.

**An overview of Track II:** "Topics in Quality of Life Instrument Development and Validation" These methods workshops provide “hands-on” training experience in advanced methods for conceptualization, development, and validation of self-report-based quality of life data. Participants will learn the principles and techniques of advanced psychometric validation methods. The 2-day workshops are designed for quality of life researchers with a thorough understanding of psychometric methods who seek advanced training in the purpose and application of state of the art techniques for QOL instrument validation. Topics include development of measurement models, statistical significance, imputation of HRQL data for longitudinal studies and advances in measuring meaningfulness of change and between-group differences in QOL assessments.

### **Track II, Workshops 1 & 2 (Monday, 9am-5pm)**

#### **Clinical and statistical significance: differences and similarities**

*Jeff Sloan, PhD, Mayo Clinic, Rochester, MN and Tara Symonds, Pfizer Ltd., Sandwich, Kent, United Kingdom*

In this session, the literature and approaches used to interpret the clinical significance of changes in HRQL scores are summarized. Differences and similarities between clinical and statistical significance are explored. Examples are drawn primarily from clinical oncology trials; hands-on experience in the design and analysis of HRQL endpoints is included. Also to be included are presentation and discussion of key findings from a recently held meeting at the Mayo Clinic in Rochester, Minnesota which focused on various aspects of clinical significance methodology and outcomes. The meeting was attended by some of the world's leading QOL researchers.

## ISOQOL presents workshop series...

You are invited to attend the second ISOQOL-sponsored series of seminars in state-of-the-art research methods. These intermediate and advanced workshops are intended to provide a hands-on training experience for those persons interested in developing HRQL instruments, evaluating their measurement characteristics, and designing studies and analyzing data from their use within longitudinal studies.

The purpose of the workshops is to help those in the research community, private industry, managed care companies, third-party payers, policymakers, and statisticians better understand HRQL measurement and interpretation of self-report data.

The seminars are divided into two tracks. Track I includes workshops that address HRQL instrument development and psychometric evaluation; conducting cognitive interviews and focus groups; testing reliability, validity and responsiveness of multiple-item rating scales; and identifying (clinically) meaningful change and important differences in HRQL assessments between groups. Track II includes workshops that focus on analysis of HRQL data. The following topics are addressed in this track: analysis of longitudinal studies with missing HRQL data; methods for multidimensional and repeated measures; and imputation of non-randomly missing HRQL data within longitudinal studies.

The workshops will be held on 5-6 February 2001 at the Hotel Washington, located at Pennsylvania Avenue at 15th Street in Washington, DC. Each workshop will be limited to 50 participants to allow for maximum interaction between faculty and participants.

Rick Berzon, DrPH  
Chair, ISOQOL Education Committee

### Workshops objectives:

These intermediate and advanced hands-on workshops are designed to help participants:

- ~ Understand the science of measuring constructs and attributes in people
- ~ Develop and test HRQL instruments
- ~ Use HRQL instruments in clinical trials and clinical practice
- ~ Conduct cognitive interviews and focus groups
- ~ Analyze and interpret self-report data from longitudinal studies
- ~ Handle repeated observations subject to missing data
- ~ Impute HRQL data in longitudinal studies
- ~ Answer the question, "How much of a change in a HRQL instrument is meaningful?"

### How to Register

Send completed registration form with payment to ISOQOL, 6728 Old McLean Village Drive, McLean, VA 22101-3906, or for credit card payments only, fax form with credit card information to 703-556-8729. Payment may be made by check, money order, or credit card. **Registration must include payment or an original purchase order.**

### About the Hotel

The Hotel Washington is located at Pennsylvania Avenue and 15th Street, N.W. The prime location of Hotel Washington overlooks the White House, only minutes to all major attractions, and only a few blocks to Metro Center and The Shops. The hotel is only 10 minutes from National Airport and convenient to the Metrorail system.

The special meeting room rates are \$128 single/double occupancy. Reservations should be made by calling the hotel directly at 202-638-5900 or 1-800-424-9540. Be sure to tell them you are with the ISOQOL meeting. **All reservations should be received by the hotel no later than January 5, 2001.**

### Cancellation Policy

All cancellations and refund requests must be received in writing. There will be a \$50 administrative fee assessed to each cancellation received by January 3. Cancellations received between January 3 and February 2 will be assessed a \$100 fee. 50% of the registration fee will be returned for cancellations received after the meeting dates.

### Networking Cocktail Reception

Each meeting registration includes the opportunity to network during a complimentary one-hour cocktail reception on Monday evening!

### For Additional Information

For more information please contact the ISOQOL Executive Office at 6728 Old McLean Village Drive, McLean, VA 22101-3906 USA; Phone: 703-556-9222; FAX: 703-556-8729; Email: [info@isoqol.org](mailto:info@isoqol.org). Visit our web site: [WWW.ISOQOL.ORG](http://WWW.ISOQOL.ORG)