



International Society for Quality of Life Research

Volume 9 Issue 1

Newsletter for ISOQOL Members

April 2004

PRESIDENT'S MESSAGE

Albert Wu, MPH, MD
Baltimore, MD, USA

I should start by thanking ISOQOL President-Elect David Feeny for filling in for me during most of the month of February, while I was preoccupied with acute wedding planning (better known as crisis management), getting married and honeymooning.

What is married life like? As far as I can tell, it involves much more sun, relaxation, exercise, and lying on the beach than being single. On the other hand, I may be confusing "married life" with the week we spent on St. Lucia.

Even (?) with the disruptions afforded by personal and work life, the ISOQOL executive committee (past, current and upcoming president, and treasurer) has been keeping on top of things with a monthly conference call. We are excited about ISOQOL activities planned for 2004.

There are encouraging grass-roots developments in the area of ISOQOL's special interest groups (SIGs). Rather than postulating groups and asking who might be interested, we are encouraging members with a particular focus to organize themselves. Bursting into the lead is a SIG concentrating on the use of QOL measures in clinical practice. The Clinical Practice SIG has constituted an organizing committee, defined its mission, and drafted an invitation to potential members. ISOQOL will be providing a webpage for the group on our website, which will include an electronic bulletin board to promote discourse, and space for other postings. Madeleine King and the able

organizers of ISOQOL Hong Kong 2004 will provide time during the meeting for this and other SIGs to meet face-to-face.

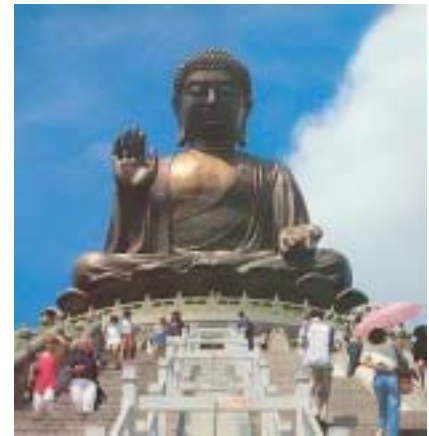
All of this provides a template for other groups in our re-invigorated stable of interest groups. Other SIGs are coalescing around topics including "Translation / Cultural Adaptation," "Students / Young Investigators," and "Individualized QOL Assessment." There will likely be more to come. Watch this space, the ISOQOL website, and your email for updates.

Speaking of meetings, I am eagerly anticipating two important ISOQOL conferences in 2004.

Dennis Revicki and Bill Lenderking have kicked into overdrive aiming towards Boston which will be the location of ISOQOL's major North American event in 2004. "Stating the Art: Advancing Outcomes Research Methodology and Clinical Applications" is more than a workshop on steroids. It promises to provide a balanced menu of course offerings as well as original research selected from the many high quality abstracts that were submitted. Plan on attending June 27-29 at the Boston Park Plaza Hotel.

At the same time, Boston will not upstage our main event, our Annual Meeting in Hong Kong, October 16-19. Plans are in full swing for what is likely to be the most important QOL meeting to be held in Asia. Madeleine King, together with Kwok-Fai Leung and Margaret Tay, have been working tirelessly. This meeting is of great importance to so many people, particularly from Pacific Rim nations, that it is bound to be a smash. Plan now on putting in for travel (airfare is

less than one would think), and submitting abstracts by May 20.



*11th Annual Conference
Hong Kong
October 16 - 19, 2004*

IN THIS ISSUE . . .

ISOQOL is pleased to announce the 2004 candidates for this year's leadership election. Bios for each candidate and a ballot are enclosed. Please review carefully and submit your completed ballot by June 30, 2004. Make your voice heard!

ISOQOL is proud to welcome its new members for 2004 on page 11. Know someone who can benefit from being a member? Have them visit our website at www.isoqol.org to download a membership application.

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Deadline for articles for our next issue is July 31, 2004

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INTERNATIONAL QUALITY OF LIFE CONFERENCE SET FOR HONG KONG

The International Society for Quality of Life Research (ISOQOL) is pleased to announce that the 11th Annual Scientific Meeting, entitled "Harmonizing International Health-Related Quality of Life (HRQOL) Research" will be held in Hong Kong, from October 16 to 19, 2004. Abstract submissions will be accepted at www.isoqol.org through 11:59 pm EST on May 20, 2004.

The ultimate goal of health care is to improve, restore or preserve health and well-being related to health, that is, health-related quality of life (HRQOL). Since 'quality of life' can mean different things to different people at different times, the study of HRQOL is conceptually complex and methodologically challenging, and ISOQOL's annual scientific conference offers an interesting and informative mix of conceptual, methodological and practical sessions.

This year's conference, with the theme *Harmonizing International HRQOL Research*, will address the importance of integrating many perspectives. *Harmony* is the combination or adaptation of parts, elements or related things; so as to form a consistent and orderly whole. With so many cultures and languages around the globe, so many ways of defining and conceptualizing HRQOL, with so many instruments and scales to measure HRQOL, and so many different uses and users of HRQOL measures, this theme provides a timely focus for what promises to be a fascinating and rewarding conference.

The plenary sessions and special symposia will address the following topics and questions:

- Determinants of HRQOL in different countries, cultures and contexts

- Conceptualization of HRQOL - differences across cultures
- Harmonizing International HRQOL Research - What do we need to achieve and how will we do it?
- Integration of Western and Traditional Chinese Medicine (TCM) & HRQOL in TCM
- Value and use of HRQOL measures in different countries and health care systems
- Item Response Theory (IRT) and cross-cultural equivalence of HRQOL instruments
- Individualised goal attainment scaling - Do HRQOL measures reflect the treatment goals?

The keynote speaker, John Ware, has long provided leadership in harmonizing international HRQOL research, with his efforts in cross-cultural and cross-instrument calibration, and more recently in dynamic instruments bridging the gulf between individual patient management and population surveys.

During the three conference days, many distinguished speakers will provide their insights and opinions. The conference will be preceded by workshops, covering a range of topics from introductory to advanced levels. All submitted abstracts will undergo international double-blind peer review with respect to significance and scientific quality. Abstracts accepted for presentation will be published in a supplement of the journal *Quality of Life Research*, which will be distributed to all delegates.

We invite submissions for scientific papers and workshops from all countries, including the Asia-Pacific region. To assist authors whose first language is not English, we will provide linguistic assistance in the preparation of abstracts prior to submission. In addition, a range of scholarships will be available, and an optional Ambassador Program will match participants with local QOL researchers, based on research interests and

specialties. A range of social and travel events will be offered to complete the conference experience!

To submit an abstract for consideration, and to learn more about the Conference, please visit www.isoqol.org or send an email to: info@isoqol.org.

CALL FOR WORKSHOP PROPOSALS: ISOQOL 2004

We are soliciting proposals for workshops that can be offered at the ISOQOL 2004 Annual Meeting in Hong Kong. The submission form can be found at www.isoqol.org. We ask that you include the level of the workshop (basic or advanced), measurable learning objectives, the type of handouts you will be using, specification of content, a brief outline of the workshop and how you plan to organize the workshop (% lecture, % class exercise, % question and answer). All applications will be peer reviewed by Society members.

The purpose of the workshops at annual meetings is to provide educational opportunities for ISOQOL members and to raise funds for the Society. These workshops usually have two major foci: measurement and analysis and interpretation. Based on membership and meeting attendee feedback, we have decided to emphasize basic level workshops at the 2004 annual meeting in Hong Kong.

If you are interested in completing a workshop submission, please do so by **May 20, 2004**. If you would like to suggest a topic for a future workshop, please contact Carol Moinpour via email at cmoinpou@fhcrc.org.

So please contribute your ideas for workshop topics or submit a proposal for a workshop. ISOQOL benefits from your involvement in its educational mission.

ANNOUNCING THE CALL FOR THE ISOQOL "OUTSTANDING ARTICLE OF THE YEAR" AWARD

ISOQOL will continue to award the Article of the Year Award to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research that was published in a peer-reviewed journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQL research methods or theory. The ISOQOL Article of the Year Award will be presented during the award ceremony at the annual meeting of the Society.

The first author of the winning article will receive a plaque and the other authors will receive a certificate recognizing the outstanding research. In addition, four new ISOQOL memberships will be available to the winners, to be distributed at their discretion.

Any HRQL research article written by any author(s) that was published for the first time during the previous calendar year in a peer reviewed journal, will be eligible if nominated for this award by an active member of ISOQOL.

Any ISOQOL member may nominate an article by completing and submitting a nomination package. Self-nomination is permitted. If more than one person nominates a particular published article for this award, a Lead Nominator will be assigned to assemble all nomination documents, submit the nomination package, and serve as the correspondent for all questions regarding the nomination. The deadline to submit a nomination is **June 15, 2004**.

For each nomination, a Nomination Package consisting of the following should be submitted to the ISOQOL Article of the Year Taskforce (Note: materials that are submitted with the nomination CANNOT be returned):

1. A complete copy of the published article must accompany the nomination.
2. A nomination letter should be provided that states why the article represents an outstanding contribution to the field of HRQL and describes how it advances HRQL research, clinical application or affects health policy.
3. Nomination will identify the author(s) and provide the full citation for the article.

The ISOQOL Board of Directors will appoint a Jury of ISOQOL members and a Jury Chair to serve as reviewers for this award. Jury members will be chosen based on their expertise in areas addressed in the articles submitted. If an article written by a member of the jury panel is nominated for the award, that Jury member will be removed from the Jury for the current year and the Board of Directors will appoint another ISOQOL member to serve on the Jury in his or her place.

After each member of the Jury reviews each article, the Jury will recommend the single article that promises to be the most significant advancement to HRQL research from all those nominated each year based on its scientific quality and societal relevance.

Should you have any questions regarding the Article of the Year award, please contact the ISOQOL Executive Office at info@isoqol.org or call 703-556-9222.

EMERGING AREAS OF QUALITY OF LIFE RESEARCH

Carolyn Schwartz, Sc.D. and Diane Fairclough, Dr.P.H.

The field of quality of life (QOL) research has a strong foundation in several decades of empirical work, and there is substantial new growth in methods, understanding, and applications as well. In an effort to enhance awareness and attention to new areas of growth in the field, we implemented a request in Fall '03 to all the ISOQOL members who are on our electronic mailing lists. We asked our members what they thought were the emerging areas of QOL research. We indicated that we were interested in identifying areas of QOL investigation for which there has been some research, and where there is an opportunity for methodological and substantive growth. Based on the responses to this initial survey, we hope to focus more attention on these emerging areas for QOL research by the ISOQOL scientific committees and perhaps to seed the initiation of special interest groups among the membership. We would like to thank the forty-one members who responded. We have attempted to organize the responses thematically, and have used portions of the responses to illustrate the major themes.

Pragmatic Applications

Use with individuals and in routine clinical practice. A primary concern is to understand how health related QOL assessments can be used along with clinical measures to enhance medical decision making, both at the population and at the individual levels. In many diseases, we know how to measure disease severity, and we can measure HRQOL. QOL measures are increasingly used in clinical trials, but we do not always know how to use the evidence generated for the benefit of our patients. The majority of our patients, however, are not treated

within clinical trials or similar research contexts. Thus there is much interest in the possible value of QOL assessment in daily clinical practice as a means of enhancing communication, identifying QOL deficits, informing decision-making and health care actions, enhancing satisfaction with and quality of care and, eventually, in improving patients' QOL. How should we transfer the information to the clinicians and patient? Can we present the information provided by the instruments in an easy way? Is it possible to make the usage of QOL results much more realistic, reflecting the individual life styles choices/preferences and characteristics? What is the value of individual index methods that allow patient-specific weights of QOL domains? Relatively little empirical work has been done in this area. The results to date have been mixed. There are significant opportunities for both substantive and methodological research in this area. The potential payoffs are significant.

Interpretation of QOL measures. This requires a robust conceptual framework followed by empirical evidence. We are not there yet. It is crucial to facilitate the use of HRQOL instruments in clinical practice. What is clinically meaningful change, particularly integrating anchor-based and distribution-based methods? What does improved QOL translate to? What are the clinical consequences of assessing QOL? How can we develop practical methods to distinguish between changes in internal standards (i.e., recalibration response shift) and reporting biases/perceived desirability and actual enduring affective QOL? In measuring QOL, are we ever dealing with a common enough construct and metric across individuals to achieve a level where numeric scores can be combined in any meaningful way? This encompasses issues such as cognitive framing, response shift, differential item functioning in item response theory (IRT), regression to the mean (how much is error, how much is real differences in the meaning), etc.

Quality management/assurance. The application of quality of life assessment in quality management and clinical audit might be of growing interest for clinicians as well as for stakeholders. What are the strategic differences for patient-reported outcomes compared to clinical indicators? In order to further implement, future research must address the relation between process and outcome, the interpretation of quality of life changes, and how to address the problem of case-mix in comparative studies.

Methodological Development

Computer-based system for HRQOL assessment. It is increasingly possible to move QOL assessment into a computer-based format for administering questionnaires, collecting HRQOL data, and reporting results. IRT offers enormous potential for enhancing QOL assessment and interpretation. It enables computer-adaptive testing and offers the possibility to reduce or eliminate the need for a multiplicity of QOL questionnaires. How will the improvements in computer-technology and advances in modern measurement theory help to revolutionize the way we collect and report HRQOL data? What role should both private and public organizations play in this effort? Symptom-related patient-reported outcome (easy to use-easy to correlate with disease evolution) and electronic patient diaries are on the radar, but deficiencies in these approaches are starting to be demonstrated (e.g., cheating).

A new look at existing methods. Cognitive Interviewing. What can we learn about perceptions of QOL from text analysis of verbal reports, conversations and discourse in general?

Conceptual Models to Guide QOL Research

We need more research into the QOL construct and what affects QOL? How does coping influence QOL? Can clinical data be expected to co-vary with QOL ratings and why (or why not)? Some survey measures ask about aspects of

perceived health and function at a point in time and seek to identify changes in these measures by repeating the survey at a future point in time. Other measures ask respondents to recall their health perceptions over a specified recent period of time to infer the health-related quality of life lived during that period. However, we have little understanding of the day-to-day and moment-to-moment variability of these health perceptions and of factors that affect changes in health perception.

Response shift phenomena. This meta-construct refers to the idea that when individuals experience changes in health (either personally or vicariously), they may change their internal standards, their values, or their conceptualization of the target construct (e.g., quality of life). It has implications for measurement sensitivity and responsiveness, clinical trials research, cost-effectiveness research, and basic research on adaptation to illness. Do strategies for identifying mediators and confounding factors in our studies of therapy and HRQOL outcomes facilitate modeling adaptation and response shift? What are the attributes that contribute to preference generically and for specific treatments? Are they different across therapeutic areas and within therapeutic areas? Can these attributes be measured? It is proposed that subjective well-being is under homeostatic control in a manner analogous to the autonomic management of blood pressure or body temperature. Here, management is by genetically determined neurological systems that cause subjective well-being to be held within a narrow positive range for each individual. It explains why subjective and objective QOL indicators normally correlate so poorly with one another.

Special populations. How do QOL models differ across phases of life (e.g., childhood, end of life) or for distinct special populations (e.g., psychiatric disorders, obesity, cultural groups)? What constitutes QOL for children

across the developmental spectrum? Are the same constructs relevant in both children and adults? What affects QOL in children? How do parents and children reports differ and converge? In the face of a short life expectancy, what is QOL, what should we measure, and when?

QOL across cultures and economic status. To what extent do existing measures capture local or global conceptions of QOL? What are the appropriate methods and approaches to establishing cross-cultural equivalence to ensure appropriate pooling of data from international trials? What are the factors determining QOL assessments with special reference to illiteracy and poverty? What are the IRT-based analyses of questionnaire equivalence? How can we introduce 'relevant and appropriate' HRQOL tools to routine clinical investigations around the world to gain standard data globally? What is the role of QOL measures in cross-cultural epidemiology? Do representative population studies show similarities/differences between or within cultural subgroups? What does this mean for the organization of health care?

Will the Seed Grow into New Growth?

We hope that this newsletter article will serve to further the development of interest groups, symposium submissions, and other venues for moving these emerging areas of research forward. If other topics come to mind, please let us know by sending an e-mail to info@isoqol.org and include "Emerging Issues" in the subject line of your e-mail.

***Editor's Note:** This column about ISOQOL members will appear as often as there is news worthy of note. Members are encouraged to submit information about new positions, awards, assignments, and memberships of themselves and/or their colleagues.*

Please keep announcements brief, ie, one or two short paragraphs maximum length. Given space limitations, the editor reserves the right to abbreviate contributions exceeding the recommended length.

Marcie Parker, PhD, CFLE has recently given or will give presentations on her research at the 18th National Conference on Chronic Disease Prevention and Control, the 10th Annual Qualitative Health Research Conference, and the Minnesota Council on Family Relations Annual Conference. Her review of the videotape 'Thou Shalt Honor' has appeared in *The Gerontologist*. Her article on 'Healthy Lifestyle Coaching: Motivational Interviewing and Stages of Change: Outcomes on What Does and Does Not Work' was recently published online. Parker is Principal and Senior Qualitative Researcher with Optum, one of the divisions of United HealthGroup."

William Lenderking, PhD was promoted to Director/Team Leader of Worldwide Outcomes Research at Pfizer. He continues to focus on the CNS area (Central Nervous System), providing outcomes research support for compounds in early development for depression and stroke primarily, as well as supervising projects in a number of other indications within the CNS area.

A CONVERSATION WITH PROF. JOHN BRAZIER, WINNER OF THE 'ARTICLE OF THE YEAR' AWARD BY ISOQOL, HANDED OUT DURING OUR LAST CONFERENCE IN PRAGUE

As a celebration of the tenth anniversary of ISOQOL, the Board of Directors of the society had the happy initiative of awarding the best publication in the year previous to the annual conference. Thus, in Prague, for the first time, we had the opportunity to appraise the good work that is being done in the field of HRQL. As you all know, Prof. John Brazier, in the name of his team, was awarded with the best HRQL article published in 2002. And it seems, fortunately enough, that the decision was not easy. The best paper was for: Brazier J, Roberts J, Deveril M. The estimation of a preference-based measure of health from the SF-36. *J Health Economics* 2002; 21: 271-92.

We have now the opportunity of congratulating the authors in person and gain some insight on the details and the implications of this paper directly from the first author, Prof. John Brazier.

Q. Could you summarize the aims and achievements described in your paper, which was considered the best HRQL publication in year 2002?

A. The SF-36 is one of the most widely used measures of health related quality of life and yet it cannot be used in economic evaluation. The scoring algorithms and profile scoring are not amenable to assessing cost effectiveness (e.g. a cost per point improvement in the pain dimension achieved by an intervention is not very useful to decision makers). The aim of the paper was to develop a preference-based measure for health from SF-36 for use in economic evaluation (specifically for estimating Quality

Adjusted Life Years). There were three main tasks to this study. The first was to derive a health state classification from the SF-36 that was amenable to valuation (called the SF-6D). The second was to conduct a survey of the general UK population to value a sample of state produced by the health state classification using standard gamble (n=611). Finally, we had to model the data to estimate an algorithm for valuing all states defined by the SF-6D.

Q. Why do you think this is an important contribution to HRQL measurement?

A. I am not sure I should be answering this question! Our view is that this paper shows that it is possible to take a health status measure such as the SF-36 and to develop a preference-based measure for use in economic evaluation. The paper sets out the key steps involved and this should be of value to scientists wishing to do the same with another measure, generic or specific.

Q. And what should be the next steps in this investigation? Have you made any progress in this sense, after the publication of that paper?

The next steps we identified in this line of work were to develop a preference based measure for the SF-12, to examine the information loss of moving from the SF-36 to the health state classification use for valuation (the SF-6D), to compare the new preference based measure to existing generic measures (such as the EQ-5D and HUI3) and to extend to work to other countries. We have made reasonably good progress in regard of each of these. The SF-12 version of the preference based algorithm has been completed (and accepted for publication in Medical Care). We have been comparing the discriminant validity and responsiveness of the SF-6D index to the original dimension scores and the component summaries and found they compare well though it does depend on the condition. I have been collaborating with researchers around the world in a number of comparisons of the SF-6D with the EQ-5D and HUI3, and they all seem to suggest that the

SF-6D (and indeed its parent the SF-36) suffers from a floor effect, but compared to the EQ-5D offers more discrimination at the upper end of the scale. Lastly, there has been a successful valuation of the SF-6D in Japan (with Professor Shunichi Fukahara), a pilot study in Hong Kong (Dr. Cindy Lam) and a study due to start in Singapore (Dr. Julian Thumboo).

Q. Is there any anecdote in the publication of this paper that you would like to share with the readers of the ISOQOL newsletter?

I have no specific anecdote I am afraid, but I remember it was quite a challenge convincing people in the QoL field (economists and psychometricians alike) that this could or even should be done. I think there are some who feel that psychometrics and economics are separate disciplines and so they should remain. Our view is very different.

Let me enter a more technical terrain for a few moments.

Q. Is it adequate to estimate preference-based measures from a psychometric questionnaire of health-related quality of life? Don't you need real preference estimation under uncertainty is required to properly recommend the use of these measures in decision-making?

A: A preference-based measure has two components, a descriptive system (usually referred to as the health state classification) and a tariff of values obtained from a sample of the general population. Psychometric measures provide the basis for improving the descriptive systems that are currently used in preference-based measures such as the EQ-5D and the HUI3. The challenge is in harnessing the rich descriptive data from these instruments. There is a range of possible techniques for valuing health states produced by the descriptive system, but some believe that there is only one gold standard method – the standard gamble that elicits values under conditions of uncertainty. While we used SG, I am less convinced by this

argument since all methods suffer from various biases and it is not clear that one is right and the others are wrong.

Prof. Brazier, in my opinion, you have been very active in trying to bring together two different and often separate traditions: econometrics and psychometrics. This was unusual just a few years ago. You clearly had the vision of the need of such a dialogue.

Q: How do you think we have advanced in it and how do you see this evolving in the future? Does it make any sense to keep separating these traditions?

I think there is now recognition among many QoL researchers that the two disciplines have much to offer the other. For me, economics has given a tremendous boost to the use of QoL measures – at least in the UK and similar countries that have adopted cost effectiveness as a criterion for reimbursement. Economists have reminded fellow QoL researchers that at the end of the day our job is to help people makes decisions – be they patients, clinicians or reimbursers. Economics, decision science and related branches of psychology offer important insights into QoL measures – one of which is the role of values. To me it makes no sense to keep these disciplines separate.

I think it is very encouraging that ISOQOL is planning a joint meeting with the society for Medical Decision Making next year.

Q. It has been pointed out that while psychometrics had a very well constructed framework of measurement evaluation (i.e., reliability and validity), econometric instruments base their validity on the goodness of theory (e.g., game theory) but have not developed a similar framework. Are you in agreement with this statement? Could you further clarify your position?

Validity is a slippery concept even amongst psychometricians, so I do not think economists are really that far behind. Some economists have expressed the view that it is not

possible to empirically validate a measure of subjective health – be it preference based or not – is like chasing ‘a will o’ the wisp’. Health economists have tended to emphasise the theoretical basis of their measures rather than their measurement properties because they have felt that existing measures of health related QoL are measuring the wrong concept for use in economic evaluation. Myself and others have been trying to develop ways of tested the validity of preference based measures drawing on the approaches developed in psychometrics, but with the aim of testing the properties economists are interested in, namely the ability to represent preferences. While I agree with my fellow economists that it is important to have a clear theoretical basis, there is also a tradition in experimental economics of testing validity via the predictions of your model. It is interesting that Kahneman has recently won the Nobel Prize in economics despite the fact that much of his work would be regarded as psychology.

Q. Prof. Brazier, do you see econometric work or background well represented in ISOQOL?

A: No. While there are some regular and very loyal members of ISOQOL who are economists (and I include myself in this group) I am always disappointed by the low turn out from the economics community. I think the society has tried to tempt more economists by addressing economic issues at the conference; these have tended to be too general. More economists would be attracted if there were more economic papers, particularly advanced economic paper, but achieving this needs more economists!

Q. Do you think that ISOQOL should be more active promoting the use of econometric instruments in population-based decision making?

A. I know some QoL researcher feel that their work is concerned with clinical and patient decision making. But the decision by reimbursement authorities

regarding which treatments to fund and which not to fund has to be one of the most important decisions for patients. I think ISOQOL should play a greater role in promoting the use of appropriate preference-based measures to help policy makers make decisions that ultimately maximise the well-being of the population. There are substantial commercial interests at stake in these decisions and it is important that science plays a greater role in ensuring the right measures are being used.

CONFERENCE ON IMPROVING HEALTH OUTCOMES ASSESSMENT BASED ON MODERN MEASUREMENT THEORY AND COMPUTERIZED ADAPTIVE TESTING

The National Cancer Institute (NCI) and the Drug Information Association (DIA) are co-sponsoring the conference, "Advances in Health Outcomes Measurement: Exploring the Current State and the Future of Item Response Theory, Item Banks, and Computer-Adaptive Testing." Scheduled for June 24-25, 2004, in Bethesda, MD, this conference will focus on new, innovative techniques for patient-reported outcomes assessment based on item response theory (IRT) modeling. Of special interest will be an open discussion among representatives of public and private organizations on the utility of developing and supporting public domain item banks and computerized adaptive tests for measuring key health domains such as physical functioning, depression, fatigue, and pain. Members from academia, industry and government will outline a research agenda for the future of health outcomes and behavioral science measurement.

An introductory IRT workshop, taught by Dr. Steve Reise, UCLA, will be offered the day prior to the start of the conference

To register for the conference or view the conference program on line, please visit the DIA website at: http://www.diahome.org/docs/Events/events_search_detail.cfm?EventID=04015. For preliminary content and related information, visit the NCI conference website at: <http://www.outcomes.cancer.gov/conference/irt>, or contact Bryce Reeve by e-mail at reeveb@mail.nih.gov.

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Project Director in Patient-Reported Outcomes

Mapi Values is an internationally renowned company with offices in France, the UK, the Netherlands and the USA, offering strategic consultancy

and tactical solutions in Health & Economic Outcomes. We are looking for a Project Director specialising in patient-reported outcomes (PRO) to be based in one of our European offices. These offices are in Lyon (France), near to Manchester (UK) and near to Utrecht (Netherlands). Worldwide, Mapi Values employs around 50 staff and is expanding.

Project Directors are responsible for procuring, designing and conducting health and economic outcomes research projects to support our clients' drug development and marketing plans. The successful candidate will have a postgraduate qualification in a relevant topic and experience of running PRO projects within the pharmaceutical industry or for a consultancy. Fluency in English and French and proven organisational and client management skills are also essential, as is an understanding of European healthcare systems. Preference will be given to candidates who have worked on international projects.

Mapi Values is jointly owned by the Adelphi Group, with expertise in strategic marketing, marketing intelligence, communication and publishing support for the pharmaceutical industry and the Mapi Group, specialising in clinical and epidemiological studies. Mapi Values was formed to combine the expertise of these two groups to deliver health and economic outcomes products and services to a wide range of clients including most of the major pharmaceutical companies worldwide.

If you meet the requirements for the above position and would like to work in a dynamic environment, please apply in writing (in English), enclosing your CV to: Carole Evans PhD, Operations Director - Global, Mapi Values, Adelphi Mill, Grimshaw Lane, Bollington, Macclesfield, Cheshire SK10 5JB, UK. e-mail: carole.evans@mapivalues.com.

Stating the Art: Advancing Outcomes Research Methodology and Clinical Applications

Chairs: William Lenderking and Dennis Revicki

June 27-29, 2004

Boston Park Plaza Hotel, Boston, MA, USA

Join other QoL colleagues and immerse yourself in the latest advances in the field of outcomes research as they pertain to patient-reported outcomes. This meeting is organized into two tracks: methodology and clinical applications, so that you can stay within a single track throughout the meeting or switch according to your preference. Join us for 2 and 1/2 days of workshops, invited plenary sessions, paper sessions, poster sessions and very special social events. Don't miss this first-of-its-kind meeting guaranteed to become an ISOQOL tradition!

[Register online at www.isoqol.org](http://www.isoqol.org)

Sunday, June 27, 2004

1:00 - 4:30 pm - Workshops

1. Q-TWiST Methodology - Rich Gelber and Bernard Cole
2. Applications of Item Response Theory Modeling for Improving Health Outcomes Measurement - Bryce Reeve and Chih-Hung Chang
3. Utilities - Les Lenert
4. Introduction to Bayesian Data Analysis for Outcomes Researchers - Dennis Fryback
5. Strategies for Multiple Endpoints in Longitudinal Studies of Quality of Life - Diane Fairclough
6. Beyond the QALY: Using Conjoint Analysis to Quantify Health-Outcome Preferences - Reed Johnson and Andrew Lloyd
7. Theoretical Models of Quality of Life - Bruce Rapkin and Carolyn Schwartz
8. Quality of Life Assessment with Computerized Text Analysis - James Pennebaker and Ivan Barofsky

6:00 - 7:00 pm - Opening Reception

Monday, June 28, 2004

9:00 am - 10:00 pm - Posters on Display

9:00 - 10:30 am - Plenary Session I: State-of-the-Art of HRQOL Assessment

Presenters: Marcia Testa and Robert Kaplan

10:30 - 10:45 am - Break

10:45 am - 12:45 pm - Concurrent Sessions:

Session 1: Modern Measurement Theory and Applications

Presenters: Ronald K. Hambleton and Chih-Hung Chang

Session 2: Cognitive Sciences and Health Outcomes Assessment

Presenters: Antonio L. Freitas and Eve Wittenberg

12:45 - 2:00 pm - Lunch on your own

2:00 - 4:00 pm - Concurrent Sessions:

Session 3: Advanced Statistical Analysis I

Presenters: Joe Hogan and Sharon-Lise Normand

Session 4: Qualitative Research Methods

Presenters: James Pennebaker and Arthur Graesser

4:00 - 5:00 pm - Meet the Author Poster Session and Reception

6:00 pm - Special Evening Social Event

Tuesday, June 29, 2004

8:30 - 10:00 am Plenary II: Outcomes Research Applied

Presenters: Gordon Guyatt, David Osoba and speaker TBD from the FDA

Chair: David Osoba

10:00 - 10:15 am - Break

10:15 am - 12:15 pm - Concurrent Sessions:

Session 5: Advanced Statistical Analysis II

Presenters: Herbert Thijs and Dennis Fryback

Session 6: Theoretical Models for HRQL Research

Presenters: Julia Fox-Rushby and Joe Sirgy

12:15 pm - 1:30 pm - Lunch on your own and Continued Poster Viewing

1:30 - 3:30 pm - Concurrent Sessions:

Session 7: Experience Sampling and Daily Process Analysis

Presenters: Howard Tennen and Alex Zautra

Session 8: State of the Art Utilities/DCE/Q-TWiST

Presenters: David Feeny, Reed Johnson, Rich Gelber and Bernard Cole

3:30 - 5:00 pm - Plenary Session III: Looking to the Future of Outcomes Research

Presenter: Peter Fayers

Discussants: Chairs of Paper Sessions 1-8

Chairs: William Lenderking and Dennis Revicki

Hotel Accommodations - The Boston Park Plaza Hotel, built in 1927, serves as the headquarters hotel of the symposium. With an unmatched location, this historic hotel is adjacent to the Public Gardens with its swan boats and chic boutiques, art galleries, and restaurants of the world famous Newbury Street.

ISOQOL has negotiated a special sleeping-room rate of \$169.00, single or double, per night, plus tax. You can call them directly at 617-426-2000 or visit our website at www.isoqol.org to reserve your room online. To book, modify, or cancel a reservation, you are required to enter the password 97D2F to identify the meeting. The deadline to guarantee the special rate is June 4, 2004.

ISOQOL WELCOMES NEW MEMBERS FOR 2004

Lucy Abraham, MSc

Pfizer Global Pharmaceuticals
Sandwich, Kent, United Kingdom

Aslam Anis, PhD

Univ of British Columbia
Vancouver, BC, Canada

Eva Baró

3D Health Research
Barcelona, Catalunya, Spain

Brent Bauer

Mayo Clinic
Rochester, MN

Jennifer Beaumont, MS

Evanston Northwestern Healthcare
Evanston, IL

Sonja Boehmer, Dipl., Psych

Freie Univ Berlin
Berlin, Germany

Carole Brouwer, PhD

Julius Division Utrecht
Amsterdam, Noord Holland, The
Netherlands

Jack E. Burkhalter, PhD

Memorial Sloan-Kettering Cancer Ctr
New York, NY

Kimberly Christopher, PhD

Univ of Massachusetts - Dartmouth
North Dartmouth, MA

Paul Cleary, PhD

Harvard Medical School
Boston, MA

Theodora Cohen

Neopharm, Inc.
Lake Forest, IL

Doug Cort, PhD

University of CA - Medical Ctr
Benicia, CA

Chris Cunningham, PhD

Massey University
Wellington, New Zealand

Virginia Ellis, MA

Health Research Associates
Radlett, Herts, UK

Jose-Maria Elorza-Ricart

Parc Sanitari Pere Virgili
Barcelona, Spain

Soly Erlandsson, PhD

Univ of Trollhattan / Uddevalla
Vanersborg, Sweden

Jack E. Fincham

University of Kansas
Lawrence, KS

Ted Gawlicki, BA, MBA

Corporate Translations Inc.
Storrs, CT

Kathleen Gondek, PhD

Bayer Pharmaceuticals Corp
West Haven, CT

Kenneth Gray, BA

TELESIS Corporation
San Diego, CA

Tove Holm-Larsen

Ferring Pharmaceuticals
Copenhagen, Denmark

Steven Hope, BSc, MSc, PhD Stud

City University, London England
Bedfordshire, UK

Haley Hoy

Vanderbilt University Medical Center
Nashville, TN

Helen Q. Huang, MS

GOQ Statistical & Data Center
Buffalo, NY

David Ingledeu, PhD

University of Wales
Bangor, UK

Zarina Nahar Kabir, PhD

Karolinska Institutet
Stockholm, Sweden

Rueya D. Kocalevent, MA

Dept of Internal Medicine
Berlin, Germany

Seung Hee Kook

Chonnam Univ Hospital, S. Korea
Kwangju, South Korea

Kimary Kulig

Pfizer, Inc.
New York, NY

Jim-Shoung Lai, PhD

Medical University Hospital
Taichung Taiwan, ROC

Eun-Hyun Lee

Ajou University
Suwon, South Korea

Kit Man Lee

G10 Cancer Centre
Shatin, HK, China

Cheng-Chieh Lin, PhD

China Medical Univ Hospital
Taichung, Taiwan, ROC

Sean Lybrand

Merck Sharp & Dohme Pty Ltd.
NSW, Australia

Irene Manaras, PhD

Royal College of Surgeons of England
London, UK

Carlo Marra, Pharm.D.

University of British Columbia
Vancouver, BC Canada

Christopher McCabe, PhD

University of Sheffield
Sheffield, South Yorkshire, UK

Diane McMullen

University of Florida
Summer Field, FL

Lori Medlen

Pharmaceutical Education Associates
Santa Cruz, CA

Erin Michalak, PhD

University of British Columbia
Vancouver, BC Canada

Donald R. Miller

CHQOER
Bedford, MA

Frank Modersitzki

Department of Veterans Affairs
New York, NY

Daniel Morris

Ottawa Hlth Research Institute
Ottawa, ON Canada

Parvez Mulani, BS, MA

Abbott Labs
Abbott Park, IL

Lise Müller, RN

Coloplast A/S
Humblebaek X, Denmark

Miles Muraoka, PhD

University of Hawaii
Honolulu, HI

Vanessa Noonan, BScPT, MSc

Rick Hansen SCI Registry
Vancouver, BC Canada

Ethgen Olivier

University of Liege
Liege, Belgium

Amy Phillips, PharmD

Abbott Labs
Abbott Park, IL

Anastasia Raczek, MEd

Quality Metric Inc.
Lincoln, RI

Michael Recht

Phoenix's Children Hospital
Phoenix, AZ

Manuel Castro Salas

Universidad de Concepcion
Concepcion, Chile

Renee Saris-Baglana, PhD

Quality Metric, Inc.
Lincoln, RI

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International Society for Quality of Life Research

11th Annual Conference

October 16 - 19, 2004

The Hong Kong Academy of Medicine

Co-organized by the Hospital Authority of Hong Kong

Abstract Submission Deadline: May 20, 2004

Special social events will take place throughout the meeting. Bring your family and friends to this exciting meeting.

PRESIDENT'S AWARD *(July 31, 2004 - Deadline for Nominations for the ISOQOL President's Award)*

The goal of this award is to recognize outstanding contributions (by an individual or group) to the advancement of the quality of life field in one or more of the following areas: "education of professionals, patients or lay individuals about the value of quality of life assessment as related to health;" "promotion or execution of quality of life research or other scholarly activities;" and "facilitating or furthering policy initiatives that impact upon health-related quality of life."

Please submit your nomination package consisting of 1) a letter from the nominator specifying the nominee's contributions, 2) the curriculum vitae of the nominee, and 3) an external support letter. The deadline for nominations is **July 31, 2004**. Please send your nomination package to:

Dr. Albert Wu, President, ISOQOL Executive Office, 6728 Old McLean Village Drive, McLean, VA 22101, USA or Fax to ISOQOL Executive Office at 703-556-8729.

The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a \$1,000 honorarium and up to \$1,000 in travel expenses if the recipient plans to attend this year's Annual Conference in Hong Kong, October 16 - 19.

New Members, continued from page 11

Holger Schunemann, MD, PhD

University at Buffalo
Buffalo, NY

Claire Snyder, PhD

School of Public Health
Baltimore, MD

Abhasnee Sobhonslidsuk

Department of Medicine
Bangkok, Thailand

Jane Speight, PhD

Oxford Outcomes Ltd
Oxford, UK

Marja Stuifbergen, MSc

Erasmus MC
Rotterdam, The Netherlands

Peter Theuns, PhD

Vrije Universiteit Brussel
Brussel, Belgium

Julian Thumboo, MBBS, MRCP, FRCP, Mmed

Singapore General Hospital
Singapore, Singapore

Diane Turner-Bowker, PhD

Quality Metric Inc.
Lincoln, RI

Ron van Amsterdam

N.V. Organon
Oss, The Netherlands

Magali Rodriguez Vidal

Universidad de Concepcion
Concepcion, Chile

Robert Volk

Baylor College of Medicine
Houston, TX

Angela Williams

Glaxosmithkline R&D
Greenford, Middlesex, UK

Iinn Wisløff, MD, PhD

Dept of Hematology, Med Clinical
Oslo, Norway

Jenny Xuan Zhang

University of Calgary
Calgary, AB Canada

Yang Zhao

Eli Lilly & Company
Indianapolis, IN

ISOQOL Election 2004

Candidates for Nominations

April 2004

Special Election Notice

The ISOQOL Board is pleased to announce the 2004 candidates for this year's leadership election. Nominees for President are Peter Fayers, England and Carolyn Gotay, USA. Those nominated for the two available Board of Directors positions are: Graeme Hawthorne, Australia, William Lenderking, USA, Elaine McColl, UK, Tara Symonds, UK.

FOR THE POSITION OF PRESIDENT

Peter Fayers, PhD

Dr. Fayers is Professor of Medical Statistics at the University of Aberdeen in UK, and Associate Professor at the University of Trondheim in Norway. He has had a long interest in quality of life research, having published his first paper on the subject in 1983. He has been a member of ISOQOL since its first meeting in Brussels, and was a Board member from 2000 to 2003. He was associate editor of Quality of Life Research from 1998, and is currently the book review editor.

Peter initially developed his interests in QoL while working at the UK Medical Research Council Cancer Trials Unit. Oncology and palliative care have been two of his particular interests, and he chaired the EORTC (European Organization for Research and Treatment of Cancer) quality of life group for the 4 years until 2003. He is a founder member of Cochrane Collaboration Quality of Life Methods Group.

Peter believes in promoting and communicating the use of simple robust statistical methods that are understood by clinicians, supplemented as appropriate both by qualitative methods and by advanced statistical analyses. To this end, he authored the book Quality of Life: Assessment, Analysis and Interpretation; in 2001 this won a first prize in the British Medical Association medical book competition. Later this year a completely revised version of the previously successful book Quality of Life Assessment in Clinical Trials will be published, jointly edited by Peter and Ron Hays.

Currently, Peter is working on HRQL assessment in diverse clinical areas: oncology, palliative care, children with asthma, Alzheimer's patients, home parenteral nutrition, Paget's disease and orthopaedics. Methodological interests include the development of new instruments using qualitative, traditional psychometric and modern IRT-based methods; methods for analysing repeated measurements when there are missing data; cross-cultural analyses of HRQL data; the assessment of pain and cognitive functioning.

If elected president, Peter would encourage the Board to continue building on ISOQOL's strengths – its diverse multi-cultural membership that encompasses a wide range of disciplines and interests, and the blend of methodological research with the practical application of HRQL in studies. While previously on the Board he campaigned for providing greater added-value for members (leading to expansion of the "members only" section of the website), and he would continue to promote further member services and facilities to complement the expanding conference and educational programmes. He would also hope to further promote ISOQOL internationally with links to other national and regional organisations.

Carolyn Cook Gotay, PhD

Dr. Gotay is a Professor at the University of Hawaii's Cancer Research Center where she has worked since 1992. Following receipt of a PhD in Psychology from the University of Maryland in 1977, Carolyn's career included positions in a liberal arts college (Gettysburg College), a medical school (University of Calgary), the federal government (National Cancer Institute), and a consulting firm (EMMES Corporation). Her current research focuses primarily on quality of life in cancer survivors and includes projects to understand more about the long-term impact of cancer in a multiethnic population and interventions to improve cancer-related outcomes for cancer survivors and their families.

She is a member of the Southwest Oncology Group, where she chairs the Behavioral and Health Outcomes Subcommittee. She served as Co-Chair for the National Cancer Institute's Cancer Outcomes Measurement Working Group, and along with Joe Lipscomb and Claire

(Continued on next page)

Carolyn Cook Gotay, from previous page

Snyder, edited the text, Outcomes Assessment in Cancer. She chairs the Hawaii-Pacific, Inc. American Cancer Society's Breast Cancer Detection Core Committee and is on the Board of Directors for the Hawaii Komen Foundation affiliate. Carolyn is a Fellow of the American Psychological Association and was recently named "Professor of Survivorship" by the Susan G. Komen Foundation.

At the Orlando ISOQOL meeting, Carolyn was surprised to be introduced as one of the pioneers of quality of life research. While this "title" was somewhat shocking (as she had never thought of herself in such terms), Carolyn came to the realization that the statement was somewhat true for her and many ISOQOL members. In fact, the growth of the field over a short period of time is stunning, as is ISOQOL's development. The challenge now is to build on that foundation: to continue to work with our multidisciplinary colleagues to ensure our work is translated into practice and policy, to ensure that our international society encourages investigations of quality of life across the globe, and to promote the active participation of a new generation of quality of life researchers.

FOR THE POSITION OF BOARD MEMBER

Graeme Hawthorne, PhD

Graeme Hawthorne is Principal Research Fellow at the Australian Centre for Posttraumatic Mental Health, Department of Psychiatry at the University of Melbourne, Australia. He has been working in health related quality of life (HRQoL) measurement for over 10 years during which time he has been either author or co-author of several scales (including the *Assessment of Quality of Life* (AQoL), a leading utility instrument). He is head of the WHO Quality of Life Australian Field Centre, which has participated in the development and validation of the *WHOQOL-100*, *WHOQOL-Bref* and *WHOQOL-OLD*, and was one of the foundation members of the OZQoL Group. His other HRQoL instrument validation work has had a particular emphasis on utility instruments, including the *EQ5D*, *HUI-3*, *15D* and *SF6D*. Other instruments which he has reviewed or validated include the *Quality of Life in Depression Scale* (QLDS), the *SF-36* and *SF-12*. He has written HRQoL reviews for the Australian Pharmaceutical Benefits Advisory Committee and the Australian Department of Health and Ageing.

In addition to HRQoL measurement, his current research covers the effect on quality of life of posttraumatic stress disorder, mental health conditions (e.g. depression, schizophrenia), cochlear implants, incontinence, and the elderly. In the last 10 years, he has been co-principal investigator on over 26 research projects which have been funded through Australian competitive research grants. He has published over 80 papers and reports.

Of particular interest are the challenges of health program evaluation, research design and data analysis. In this capacity he has been a HRQoL consultant to several international studies. Evaluations include various health promotion interventions (e.g. heart health programs), coordinated care trials, hospital post-intensive care programs, pulmonary rehabilitation, hospital emergency departments, psychotherapy programs, drug education, and driving behaviour and training. He is a reviewer for seven academic journals.

If elected to the ISOQOL Board, he would be able to assist with furthering the development of ISOQOL through his comprehensive understanding of health-related quality of life measurement, his broad experience as a program evaluator across many public and clinical health fields, and he would bring to the Board a broad perspective through representation of the Australian research community.

William Lenderking, PhD

Dr. Lenderking is a licensed psychologist who has specialized in research in quality of life since 1990. He spent 4 years at Harvard School of Public Health, where he completed a post-doctoral fellowship working in the Quality of Life Section of the AIDS Clinical Trials Group, helping to evaluate the impact of new antiretroviral medications on patients with AIDS, and then worked as Research Associate in the Department of Biostatistics. He also completed a post-doctoral fellowship at Massachusetts General Hospital in the HIV and Psychiatry Clinic, where he had the opportunity to work with many patients and their family members struggling to maintain their quality of life while dealing with HIV/AIDS. He remained on staff at MGH from 1990-2000, and was an Assistant Clinical Professor of Psychiatry at Harvard Medical School. From 1994-1998, Dr. Lenderking was a Senior Research Scientist at Phase V Technologies, where he continued to conduct research in quality of life, completing projects and developing scales in narcolepsy, HIV/AIDS, migraine and treatment satisfaction, urge urinary incontinence, depression, and many other conditions. During this time, he continued to conduct behavioral research in HIV/AIDS as well, publishing several papers on risk factors related to AIDS-related risk-taking. He also completed consulting projects for the United Nations (on cognitive impairment in HIV infection), and worked on the development of the Brief Male Sexual Function Inventory, a scale to measure sexual dysfunction in men. From 1998-2000, Dr. Lenderking worked for Abt Associates, as an early staff member of the pharmacoeconomics and outcomes research division of AACT and serving as the psychometrician for the HIV Vaccine Trials Network (HIVNET). In 2000, Dr. Lenderking joined Pfizer Inc in Groton, CT, as Director of Outcomes Research in the CNS area, and has worked

(Continued on next page)

For the Position of Board Member (continued)

William Lenderking, from previous page

on projects in depression, stroke, traumatic brain injury, HIV, and pain for Pfizer, where he has had the opportunity to work on many international translations of health status instruments. Dr. Lenderking is currently the co-editor of *Value in Health* for quality-of-life issues. He has maintained an independent clinical practice from 1993 to the present. He is currently involved in planning the ISOQOL interim meeting in June in Boston with Dennis Revicki as co-chair.

“I am honored to be nominated for a position on the Board of ISOQOL. I feel that with my background as academic, consultant, clinician, psychometrician, and in industry, I understand the many diverse constituencies within ISOQOL. This diversity is a great strength of ISOQOL and should be cultivated. I will work hard to maintain the high scientific standards of ISOQOL, to help it grow through both attracting new members (especially students) and retaining current members, and to help strengthen the organization in any way I can. This is an exciting time for outcomes research, and our society has a great opportunity to influence and improve the provision of health care in the future, and I hope to be a part of that mission.”

Elaine McColl, MSc

Ms. McColl is the Director of the Clinical Trials Unit at the University of Newcastle upon Tyne. A social scientist by background, she has been involved in research into patient-reported outcomes and quality of life since 1990. In the early 1990s, she was a member of the European Research Group on Health Outcomes, and during that time co-edited the book *Outcome measures in primary and outpatient care*. Since then she has published several papers and book chapters on quality of life assessment and continue with a vibrant programme of research in this area. She also plays an active role in quality of life affairs at an international level, as a founding member of the International Study Group on Cognitive Aspects of Quality of Life Research and as chair of the Concepts and Methods Review Sub-Group of the Cochrane Health Related Quality of Life Methodology Group. She is an Associate Editor of *Quality of Life Research* and referee for this and other journals in the field. She also contributes in several ways to ISOQOL: she co-chaired the Abstracts Review committee for the 2003 Prague meeting; has acted as a mentor at the Orlando and Prague meetings; has presented posters, oral presentations and/or workshops at each meeting since Baltimore. Most importantly, she has been chair of the Membership Committee for the past 18 months and has very much enjoyed working with colleagues from around the world in an effort to promote and enhance the benefits of ISOQOL membership. If elected to the Board, she would continue to address the issue of responsiveness to current and potential members' needs. She passionately believes that ISOQOL should be inclusive, not just a club for an elite inner circle. She is very committed to fostering Early Career Investigators, and would seek to broaden what we provide for this group beyond the Mentor-Mentee pairings at the annual meetings.

Tara Symonds, PhD

Dr. Symonds is a Health Psychologist and works for Pfizer in the Outcomes Research Department at the Research and Development site at Sandwich in the UK. She has worked at Pfizer for the past 5.5 years, prior to this she worked in academia, at various Universities in the UK (Huddersfield University, University of Central Lancashire, and Staffordshire University). She has research experience in Urology, Pain, Dermatology, and HIV/AIDS. She is currently a reviewer for the Quality of Life Research journal.

Her main research interest over the past 5 years has been on how best to interpret Patient Reported Endpoint (PRO) score changes based on working in an unprecedented area where PRO endpoints are often the primary efficacy endpoint, namely Sexual Health. She was actively involved in the first very successful Clinical Significance Consensus Working Group, leading one of its writing teams. She continues to be involved in this group, currently looking at how to use and interpret PRO scores in clinical practice. She previously served on the Educational Section of ISOQOL and in this capacity conducted a number of workshops on how to assess the clinical meaningfulness of QOL results. By becoming a member of the ISOQOL board her main aim would be to strive to keep the momentum going around addressing the clinical significance issue. We need to be more routinely considering this in our on-going research, especially when presenting data on a new questionnaire. If we cannot resolve this issue, or certainly make significant inroads into resolving it, QOL will stagnate and may even be its downfall.

Please find enclosed a ballot for this year's nominees. Please take a moment to vote for your fellow members and return your ballot to the ISOQOL Executive Office by June 30, 2004.

INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH (ISOQOL) 2004 LEADERSHIP BALLOT

Dear ISOQOL Member:

Please vote for a candidate by marking an **X** in the box left of the candidate's name. Once you have voted, please mail or fax your ballot to the ISOQOL Executive Office **no later than June 30** in order to be counted in the election.

CANDIDATES FOR THE POSITION OF PRESIDENT-ELECT (vote for only one):

- | | | | |
|--------------------------|---------------------------|-------------------------------|------------|
| <input type="checkbox"/> | Peter Fayers | University of Aberdeen | UK |
| <input type="checkbox"/> | Carolyn Cook Gotay | University of Hawaii | USA |

CANDIDATES FOR THE POSITION OF BOARD MEMBER (vote for no more than two candidates):

- | | | | |
|--------------------------|---------------------------|--|------------------|
| <input type="checkbox"/> | Graeme Hawthorne | University of Melbourne | Australia |
| <input type="checkbox"/> | William Lenderking | Pfizer Inc. | USA |
| <input type="checkbox"/> | Elaine McColl | University of Newcastle upon Tyne | UK |
| <input type="checkbox"/> | Tara Symonds | Pfizer Inc. | UK |

PRINT NAME: _____

Please print name clearly. Illegible names will not be counted.

SIGNATURE: _____

Cast your ballot today and mail or fax it by June 30, 2004 to:

*ISOQOL Executive Office
6728 Old McLean Village Drive
McLean, Virginia 22101-3906 USA
FAX: 703-556-8729*