

17th Annual Conference of the International Society for Quality of Life Research



# Translating Quality of Life Measurement into Decision Making

October 27-30, 2010 London, UK

London Hilton Metropole



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### Schedule-at-a-Glance

Wednesday October 27		Thursday October 28		Friday October 29		Saturday October 30	
7:00am	Registration Opens Room	7:00am	Registration and Exhibits West Wing Lobby	7:00am	Registration and Exhibits West Wing Lobby	7:00am	Registration and Exhibits West Wing Lobby
9:00am- 4:00pm	Workshop Analysis of Longitudinal Studies of HRQOL in SAS, SPSS and R	8:00am- 6:45pm 7:45am-	Poster Session 1 on Display Viscount Suite and Foyer Welcome Remarks	8:00am- 6:45pm 7:45am-	Poster Session 2 on display Viscount Suite and Foyer President's Address	7:45am- 9:15am 8:00am-	Concurrent Symposia See page 31 Poster Session 3 on display
9:00am- 12:00pm 12:00pm	Clarence Room  Workshops  1 Belgrave Room  2 Berkeley Room  3 Chelsea/Richmond Room  4 Waterloo/Tower Room  5 Regents Room  6 Will not be presented  7 St. James Room  8 Cadogan Room  Lunch on your own  Workshops	8:00am 8:00am- 9:30am 9:45am- 11:15am 11:30am- 1:00pm	Plenary Session Psychometric Methods for Developing and Evaluating Rating Scales: Why I Do What I Do Sandringham Suite  Oral Concurrent Sessions See page 14  Oral Concurrent Sessions See page 16	8:00am 8:00am- 9:30am 9:45am- 11:15am 11:30am- 1:00pm	Sandringham Suite  Plenary Session The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities Sandringham Suite  Oral Concurrent Sessions See page 22  Oral Concurrent Sessions See page 24	3:30pm 9:30am- 9:45am 9:45am- 11:15am 11:30am- 1:00pm	President's Award Lecture Sandringham Suite  Plenary Session Dissemination and Integration of PRO Data into Clinical Care Sandringham Suite  Plenary Session Discussion with Health Care Luminaries Sandringham Suite
4:00pm	9 Waterloo/Tower Room 10 Belgrave Room 11 Will not be presented 12 Berkeley Room 13 St. James Room 14 Chelsea/Richmond Room 15 Cadogan Room 16 Regents Room  Mentor-Mentee Reception	2:00pm- 3:30pm 3:45pm- 5:15pm 5:15pm- 6:45pm	Concurrent Symposia See page 18  Oral Concurrent Sessions See page 20  Reception and Meet the Author Poster Session Viscount Suite and Foyer	2:00pm- 3:30pm 3:45pm- 5:15pm 5:15pm- 6:45pm	Concurrent Symposia See page 26  Oral Concurrent Sessions See page 28  Reception and Meet the Author Poster Session Viscount Suite and Foyer	1:00pm- 2:30pm 2:30pm- 3:30pm 3:30pm- 5:15pm	Reception and Meet the Author Poster Session Viscount Suite and Foyer  ISOQOL Business Meeting Sovereign Suite  Meet the Experts: Modern Test Theory and the Future
5:30pm 5:30pm 7:00pm 7:00pm 8:30pm	Welcome Reception Balmore Suite  Special Session: Getting G Theory to Work for You	6:45pm	SIG Meeitngs   Committee Meetings Fundraiding Committee York Room	6:45pm	SIG Meeitngs   Committee Meetings  Strategic Partnership Committee Hilton Meeting Rooms 1-6	7:00 pm	of Health Measurement Sovereign Suite  Conference Dinner Viscount Suite
PL W RE TI AN	LEASE NOTE: ORKSHOPS EQUIRE ADDI- IONAL FEES ID REGISTRA- FION IS RE- QUIRED.		Balmoral Suite		New Investigator SIG Balmoral Suite		

## 2010 Welcome

On behalf of the 70 members of the Scientific Program Committee, we welcome you to London, home to the 17th Annual Meeting of ISOQOL. We hope you will enjoy both the scientific program and host city over the next few days.



Co-Chair: Stefan Cano, PhD, *UK* 



Co-Chair: Jane Scott, PhD, *UK* 

This year's meeting focuses on the theme "Translating Quality of Life Measurement into Decision-Making". This theme represents a triad of topical areas, which link the use of patient rating scales from practice to policy via the cornerstone of psychometrics. We will explore the key issues of the day through plenary sessions that will address the use of patient rating scales for decision making in clinical research, clinical trials and national health policy, as well as addressing important questions about the science that underpins their use. To complement and build on the plenary presentations, we have three invited symposia that focus on specific topics in methodology, clinical research and clinical practice and two question and answer sessions that provide an opportunity for delegates to interact with some of the key luminary figures in policy making and modern psychometric methods. Also new this year are several inovations: a poster workshop, and prizes for best posters representing the three tracks of the conference (i.e., clinical practice, clinical research and methodology). The remaining core of the conference program is made up from over three hundred presentations during the many symposia, oral, and poster presentations. We have split these presentations into tracks reflecting the three key elements of the program to help you navigate the busy and exciting program.

We invite you to make the most of your time in the city and enjoy the sights, sounds and flavours of London. We look forward to welcoming you in person at the opening reception Wednesday night and winding down during the conference closing dinner on Saturday at the London Hilton Metropole Hotel. For your free time, your registration packet has hints, tips and suggestions for local sightseeing. Finally, and as per ISOQOL tradition, we would like to give something back to local charities each year. So, this year you can bring a book to donate, donate your conference bag at the end of the meeting, or make a cash donation all of which will go to support the Red Cross.

Thank you for joining us for this year's annual meeting in London. At the end of the meeting, we hope you will have been stimulated with new ideas, have made new contacts and friends, and maybe even have learned something new.

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<sup>\*</sup> symposium reviewer

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#### About ISOQOL/General Information

# **About ISOQOL**

#### **ISOQOL Mission**

To advance the scientific study of health-related quality of life and other patient-centered outcomes to identify effective interventions, enhance the quality of health care and promote the health of populations.

#### **ISOQOL Special Interest Groups**

Special Interest Groups have been established to facilitate communications between researchers with specific interests, ranging from methodology (e.g. clinical applications; cross-cultural research and translation methods), to applications of QoL in particular populations (e.g., HIV/AIDS). For more information, visit our website at www.isogol.org, or attend the SIG meetings while in New Orleans.

#### **ISOQOL Committees**

ISOQOL members are encouraged to serve on the following committees and subcommittees:

Membership; Communications: Newsletter, Website; Finances and Budget Planning: Fundraising and Grantwriting; Education: Scholarships, Workshops; Governance; Meetings Policy, Planning and Evaluation; Scientific Program; Strategic Partnerships; and Industry Advisory.

### General Information

#### Conference Venue

All plenary, invited, oral & poster sessions and training workshops will take place at the **Hilton Metropole**. See page 63 for the hotel floor plans.

#### Registration

**Registration fees include:** participation in the Conference and access to the exhibition area; abstracts and program; Welcome Reception on Wednesday; refreshments/coffee breaks on Thursday, Friday and Saturday; and lunch on Friday for those who have registered for the Business Meeting. **Workshop attendance** is separate from the regular conference registration, and requires a separate registration. If you are registered for a workshop (or two), there will be a label on your registration envelope which will indicate which workshop(s) you are scheduled to attend. There may be limited availability if you would like to sign up on-site for a workshop – please visit the ISOQOL Registration Desk in the **Room** for more information.

### Opening Reception (Wednesday, October 27, 5:30 - 7:00 pm)

An opening reception will be held in the **Balmoral Suite**. Start the meeting by visiting with old friends and meeting new colleagues.

#### **Poster Sessions**

The Poster Sessions will take place in the **Viscount Suite**. Each poster has been assigned a specific number, which can be found in the program just before the abstract title. Each poster station will be numbered—please mount your poster at the correct poster number/station.

### **Important Information on Poster Tours**

This year, the Program Committee will be offering "Poster Tours" during the Meet the Author sessions on Thursday, Friday and Saturday. These tours will be led by an expert who will walk with a group of interested participants to selected posters and discuss the study and its findings with the author and the tour participants. Poster Tours will begin 15 minutes into the Poster Sessions and will last approximately 30 minutes. The tours are as follows: Thursday: **general methods** (led by Jeff Sloan) and **clinical** (led by Ron Hays); Friday: **health policy** (led by Albert Wu) and **clinical** (led by Carolyn Schwartz); and Saturday: **pediatrics** (led by Anne Riley) and **cancer** (led by Galina Velikova). Participants should meet by the Message Board at the ISOQOL Registration Desk at the beginning of the poster session in order to join the tour. See the program for the time of each Poster Tour session.

# General Information, continued

#### Annual Business Meeting (Saturday, October 30, 2:30 - 3:30 pm)

This session will include brief updates from the ISOQOL Leadership regarding the previous year's activities, plans for the upcoming year, and we will have an open discussion about how the Society can serve you, and how you can help the Society through direct involvement. ISOQOL encourages everyone, whether you are currently a member or not, to attend this session. This is a great opportunity to learn more about what ISOQOL has to offer you, as well as brainstorm new initiatives that will better serve you.

#### ISOQOL Employment Exchange Program

Again this year, ISOQOL will have the Employment Exchange program. The program allows institutions to post job opportunities, and qualified applicants looking for employment to post their resume during the meeting. A notebook with job announcements and resumes will be located near the ISOQOL membership table.

#### Mentor/Mentee Session (Wednesday, October 27, 4:30 - 5:30 pm)

ISOQOL's Mentor/Mentee program of matching new investigators with mentors in the QOL field will take place in the **Windsor Room** on the ?? floor of the hotel.

#### Conference Dinner (Saturday, October 30, 7:00 - 10:00 pm)

A conference dinner will be held in the **Viscount Suite**. Please see Meeting Registration Desk for directions and details.

**The Awards and Closing Ceremony** will also be held at this time. The conference dinner is not included in the registration fee. Unless a ticket was purchased in advance, the additional on-site fee is \$105US for conference attendees and their guests.

The organizer reserves the right to cancel events. In the unlikely event of cancellation, the admission charge will be refunded or transferred to another event chosen by the delegate. No other claim will be accepted.

#### Scientific Awards

The following prestigious Annual Awards will be presented during the Awards Ceremony at the Conference Dinner.

The **New Investigator/Student Awards** recognize the best overall oral and poster presentations made by full-time students and investigators in the early stages of their career in HRQOL research. The finalists will be recognized, and the winners announced at the Conference Dinner.

**The President's Award** is given to an individual who has advanced HRQOL research and has made outstanding contributions to ISOQOL in one or more of the following areas: education of professionals, patients or lay individuals about HRQOL's value; promotion or execution of HRQOL or other scholarly activities; and facilitating or furthering policy initiatives that have an impact on HRQOL. The awardee is selected by the Executive Committee and endorsed by the Board. This year's President's Award recipient is **????** of **????**.

The **Outstanding Article of the Year Award** recognizes the single best article dedicated to health-related quality of life research published in *Quality of Life Research* 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 HRQOL research methods or theory. The finalists will be recognized, and the winner announced at the Conference Dinner.

# **Program Schedule**

Wednesday, October 27, 2010

7:00 am - 5:00 pm **Registration** *Room* 

9:00 am - 4:00 pm Full Day Workshop Clarence Room

Analysis of Longitudinal Studies of HRQOL in SAS, SPSS and R

Instructor: Diane Fairclough, DrPH, Colorado School of Public Health, Denver, CO USA

This morning/afternoon workshop will provide a tutorial of the analysis of longitudinal studies with missing data. During the morning we will start with models that assume the dropout is ignorable given the analysis incorporates all available data. We consider two designs: where time is an ordered category (e.g. pre, during, post) or time is a continuous construct. For both, we will first discuss the assumptions underlying each model and then will go through the steps of fitting the model in SAS, SPSS and R. During the afternoon, we will continue to work with the above models and also consider a few analysis techniques that can be used as sensitivity analysis when there is concern about the non-ignorable assumptions. The workshop will include time for practice with datasets that will be provided. Participant are encouraged (but not required) to bring laptop computers with SAS, SPSS or R installed. Level: Advanced

9:00 am - 12:00 pm Morning Workshops

#### Workshop 1

Belgrave Room

An Introduction to Pediatric Patient Report Outcomes and their Inclusion as Endpoints in Pediatric Clinical Trials

Instructors: Rob Arbuckle, MSc, Mapi Values Ltd, Bollington, Cheshire, UK; Linda Abetz-Webb, MA, Mapi Values Ltd, Bollington, Cheshire, UK; Robyn Carson, MPH, Forest Research Institute, Jersey City, NJ, USA; Barbara Edelman Lewis, PhD, Ironwood Pharmaceuticals, Cambridge, MA, USA and Olivier Chassany, PhD, Hopitaux de Paris, Paris, France

Patient reported outcomes (PROs) are often required as primary endpoints in pediatric clinical trials, or are of value as key secondary endpoints. However, pediatric PRO selection/development and pediatric clinical trial design are both complex and challenging. When, in relation to the adult program, should you plan for pediatric trials? Are all PRO development methods applicable to pediatrics PROs, including observer ratings? How do you design developmentally appropriate PROs when the age range spans 2-17 years? How do we best elicit content from children to develop pediatric PROs? At what age must we rely on observer ratings and from what age can children reliably complete a PRO themselves? What recall periods and response formats are appropriate? When should you engage with regulators and what standards do they expect? Is pooling of data across age ranges appropriate? We will explore the above issues with input from industry, regulatory and agency perspectives and with real-life examples from several disease areas including constipation/IBS, restless legs syndrome, and allergic rhinitis. Recordings of challenging pediatric interviews will be shared and creative methods for engaging with and eliciting content from children discussed. There will be the opportunity to code child interview transcripts. Level: Basic

#### Workshop 2

Berkeley Room

**Conducting Cognitive Interviews in Special Populations** 

Instructors: Carla Demuro, MS, RTI Health Solutions, Research Triangle Park, NC, USA; Dana DiBenedetti, PhD, RTI Health Solutions, Research Triangle Park, NC, USA; Sandy Lewis, BSRN, RTI Health Solutions, Research Triangle Park, NC, USA; and Sheri Fehnel, PhD, RTI Health Solutions, Research Triangle Park, NC, USA

The cognitive interview was initially developed in the early 1980's to identify sources of potential response error within surveys or questionnaires. With the release of the final FDA guidance 'Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims' (US Department of Health and Human Services, 2009), cognitive interviews have gained importance and relevance in both concept elicitation and cognitive debriefing. Standard approaches for the conduct of a cognitive interview such as think aloud, verbal probing, and concurrent and retrospective probing abound and all provide valuable insight. However, such standard approaches may lose utility in a sick or otherwise challenged population. For example,

what approach is best for use in pediatric subjects to sustain attention? How does the interview environment impact subjects with dementia, schizophrenia or other cognitive impairment? Are there special considerations in interviewing patients with communication challenges (e.g., those with severe stuttering, visual impairment)? How do we ask questions about sensitive topics such as sexual functioning, risk behaviors or sexually transmitted infections without introducing bias? This workshop seeks to provide tips and techniques to guide the researcher in methods to foster a successful cognitive interview under suboptimal conditions that will meet the rigor described in the FDA guidance. *Level: Basic* 

#### Workshop 3

Chelsea/Richmond Room

Interpreting Utility (Preference-Based) Measures of Health-Related Quality of Life
Instructors: David Feeny, PhD, Kaiser Permanente Northwest, Portland, OR, USA; Allyson Jones, PhD,
University of Alberta, Edmonton, AB, Canada and Maria Santana, PhD, University of Alberta Hospital,
Edmonton, AB, Canada

The Workshop will be at an advanced level, focusing on the interpretation of utility scores from direct and multi-attribute (indirect) approaches to preference-based measurement. The direct approaches will include the visual analogue scale (Feeling Thermometer), time tradeoff, and standard gamble. Major multi-attribute utility measures will include the EQ-5D, Health Utilities Index (HUI), and Short-Form 6D. The Workshop will include hands-on experience in the direct elicitation of preference scores for a health state, the completion of questionnaires from several instruments (EQ-5D, HUI2 and HUI3, SF-6D), and the analysis and interpretation of the results. The interpretation of scores will be considered in the context of comparing groups at a point in time as well as comparing within-person change over time. Applications will be drawn from diverse clinical and population health applications including osteoarthritis of the knee, multiple sclerosis, total hip arthroplasty, lung transplantation, acute lymphoblastic leukemia, hip fracture, data from population health surveys, and the use of preference-based measures in routine clinical practice settings. Evidence on clinically important differences will be discussed. Attendees should, at a minimum, have a basic knowledge of the conceptual foundations and practical approaches of the utility approach to assessing health-related quality of life. Level: Advanced

#### Workshop 4

Waterloo/Tower Room

Everything you wanted to know about modern psychometric methods but were too afraid to ask: Part 1

Instructors: Jeremy Hobart, MD PhD, Peninsula Medical School, Plymouth, Devon, UK and Stefan Cano, PhD, Peninsula Medical School, Plymouth, Devon, UK

Confused by classical test theory? Finding item response theory inaccessible? Wrestling with Rasch analysis? Struggling with the statistics? Muddled by the math? Are you like we were: wannabe psychometricians trying to get into modern psychometric methods, but who have attended other workshops and left feeling none-the-wiser? Then this is the modern psychometric methods workshop for you. In reality the basic principles are very simple. So, we have put together a straightforward, non-technical, non-mathematical approach to modern psychometric methods that will help you begin to access the fantastically powerful and illuminating information they have to offer. In this workshop we will describe: the role of quality of life and other types of health rating scales as outcome measures; the basic principles underlying traditional psychometric methods, their limitations and drivers for modern methods; the principles underpinning modern psychometric methods; the similarities and difference between traditional and modern psychometric methods; the similarities and important differences between Rasch analysis and Item Response Theory. This workshop will also provide a hands-on instruction in using the Rasch Measurement Model (RUMM2020) software package in order to analyze data for internal construct validity; reliability; category probability curves; differential item functioning; and scaling characteristics. The three-hour workshop will be divided into three equal subsessions: lecture including descriptions of background, principles and comparison of methods; demonstration of Rasch analysis in practice; hands-on class exercise including data analyses using the RUMM 2030 program, and question & answer session (attendees should bring their laptops to the session to fully benefit from the hands on data analysis exercise). Level: Basic

#### Workshop 5

Regents Room

#### Interpretation of PRO Data within Clinical Trials

Instructors: Josephine Norquist, MS, Merck Sharp & Dohme, Corp., North Wales, PA, USA and Kathleen Wyrwich, PhD, United BioSource Corporation, Bethesda, MD, USA

Learning Objectives: (1) Understand the FDA and EMA regulatory recommendations for interpreting PRO data to support product labeling and promotional claims (2) Describe current methodology to derive at a responder definition (3) Understand use of cumulative response distribution (4) Pitfalls when applying within-person changes to between-group population differences and (5) Address the need for interpretation of between-group treatment differences. The final FDA Guidance on PRO measures no longer proposes the minimal important difference (MID) as an approach for the interpretation of PRO data in contrast to the EMA Health-Related Quality of Life Reflection Paper. Instead, an a priori responder definitions or, alternatively, cumulative distribution functions are recommended by the FDA. This methodology, however, does not assist in the identification of what should be considered a 'clinically meaningful' treatment difference. A challenge in this emerging area is that 'clinical meaningfulness' is an undefined subjective concept that may vary depending on the perspective of who is judging the clinical meaningfulness. In addition, linking treatment 'differences' on a PRO measure to treatment differences on a clinical parameter in clinical trials has methodological issues. Level: Advanced

#### Workshop 6 will not be presented

Workshop 7

St. James Room

Advanced Psychometric Methods, Part 1: Use of Exploratory and Confirmatory Factor Analyses in PRO Instrument Development and Evaluation

Instructors: Donald Stull, PhD, United BioSource Corporation, Bethesda, MD, USA; Margaret Vernon, PhD, United BioSource Corporation, Bethesda, MD, USA; Elizabeth Merikle, PhD, United BioSource Corporation, Bethesda, MD, USA

The development and psychometric evaluation of PRO instruments requires the application of a number of different techniques, including exploratory and confirmatory factor analysis (FA), and structural equation modeling (SEM). We will provide a brief overview of psychometric analyses and will then focus on the application of (1) exploratory and confirmatory factor analysis for understanding of new measures and (2) use of SEM for testing construct validity. Exploratory and confirmatory FA can be used to examine the relationships among items with a PRO measure or among different domains or multiple PRO measures. These techniques are useful for understanding the internal structure of PRO instruments and for understanding construct validity. This half-day workshop will describe the main methods of FA and illustrate these methods with examples from the instrument development literature. SEM is a powerful analytic technique that combines FA and path analysis in a simultaneous, confirmatory approach. Using SEM, the researcher can specify and evaluate hypothesized relationships between observed and latent (unobserved) constructs as well as relationships among the latent variables. SEM can also estimate the reliability and validity of measurement models which specifies relationships among the latent variables to examine construct and criterion-related validity. If the observed covariances are consistent with the model-implied covariances, the researcher has evidence supporting the construct validity of the PRO measure. This workshop will demonstrate the main methods, testing assumptions and criteria, and provide examples to illustrate the methods of SEM. Level: Advanced

#### Workshop 8

Cadogan Room

How many subjects do I need for my study? Sample size determination for studies with QoL outcomes

Instructor: Stephen Walters, PhD, University of Sheffield, Sheffield, UK

Quality of Life measures are now frequently used in clinical trials and health services research, as primary endpoints. Thus investigators are now wanting to plan studies using QoL measures, which includes questions on sample size. Sample size calculations are now mandatory for many research protocols and are required to justify the size of studies in papers before they will be accepted by journals. Sample size is critically dependent on the purpose of the study, the QoL outcome measure and how it is summarised, the proposed effect size and the method of calculating the test statistic. Whatever type of study design is used the problem of sample size must be faced. This workshop will describe how sample sizes may be estimated for a variety of different study designs using QoL outcomes. The study designs will include: two group clinical trials, cross-over trials, cross-sectional surveys and reliability studies. The consequences of comparing more than two groups or investigating several QoL outcomes simultaneously are discussed. This course will provide practical guidance on the estimation of sample size for a variety of study designs. It will feature many real and original examples, taken from the instructor's experience of analysing PROs. Content: Introduction to significance tests, P-values and power; Samples sizes for comparison of two independent groups; Sample sizes for paired designs; Sample sizes for equivalence/non-inferiority studies; Unequal groups; Multiple comparisons; Sample sizes for surveys; Sample sizes for reliability and method comparison studies; Use of computer simulation. It is expected that course participants will be familiar with statistical concepts such as: hypothesis testing; confidence intervals; simple statistical tests (e.g. t-test). Level: Basic

12:00-1:00 pm

Lunch on your own

1:00-4:00pm

Afternoon Workshops

Workshop 9

Waterloo/Tower Room

Everything you wanted to know about modern psychometric methods but were too afraid to ask: Part 2

Instructors: Jeremy Hobart, MD PhD, Peninsula Medical School, Plymouth, Devon, UK and Stefan Cano, PhD, Peninsula Medical School, Plymouth, Devon, UK

Part 2 builds on Part 1 and is a direct response to last year's feedback for more time in general, more detail on the similarities and differences between Rasch measurement and IRT, more examples of practical applications and their interpretation, and the call for whole day devoted to this critically important topic. This allows the workshop to develop further the ideas behind modern psychometric methods a little deeper but still in a non-technical and basic manner. We will provide multiple examples of the applications of Rasch measurement to scale evaluation, scale modification, new scale development, head to head scale comparisons, item banking, and the all important issue of determining clinically significant change. Level: Basic

#### Workshop 10

Belgrave Room

#### The use of R and WinBUGS in fitting I tem Response Theory models

Instructor: Yuelin Li, PhD, Memorial Sloan-Kettering Cancer Center, New York, NY, USA

This workshop is developed for behavioral scientists who want to learn how to fit IRT models with open-source statistical computer languages R and WinBUGS. This workshop is a How-To guide to IRT basic theories and a step-by-step tutorial on how to use R and WinBUGS to analyze IRT data for measurement development. R and WinBUGS are well suited for learning IRT because (among other advantages) their syntax closely resembles the IRT theories. They promote a clear understanding of the fundamental theories. Additionally, support can be sought from active online user forums. We will capitalize on these advantages to learn how to make R and WinBUGS work for your research and teaching. Participants are encouraged to bring a laptop with R and WinBUGS already installed. Participants are encouraged to go to my website (http://idecide.mskcc.org), download the sample R and WinBUGS codes, and try them before the workshop. Additional software requirements are also listed on the website. The workshop is organized as follows. We will first cover a few basic techniques in using R for general statistical analysis and data visualization. For IRT, we will use real examples from my own research to cover the basic concepts as well as the more advanced topics. The basic skills include how to select/modify items and response categories by visually inspecting the Item Characteristic Curves and the Item Information Curves. The more advanced topics will include Generalized Partial Credit Model by WinBUGS, Differential Item Function (DIF) and Computerized Adaptive Testing (CAT). CAT addresses the interactive administration of an instrument, e.g., over the web. Level: Advanced

#### Workshop 11 will not be presented

#### Workshop 12

Berkeley Room

Documenting PRO Evidence for EMA and FDA Submissions to Support Promotional and Labeling Claims Instructors: Josephine Norquist, MS Merck Sharp & Dohme, Corp., North Wales, PA, USA; Annabel Nixon, PhD, Oxford Outcomes, Oxford, Oxon, UK and Kati Copley-Merriman, MS, MBA, RTI Health Solutions, Research Triangle Park, NC, USA

This workshop will provide a detailed overview of the required evidence related to regulatory submissions in order to achieve a patient-reported outcome (PRO) label claim, and insights into procedures for documenting this evidence in the format required by regulatory authorities. The discussions will be framed by recent regulatory guidances (FDA 2009, EMA 2005) and will have a practical focus in order to guide what is, and what is not, required in order to successfully achieve a desired claim. Differences between the two regulatory guidances will be highlighted during the workshop. The first part of the workshop will examine the required evidence for the PRO instrument itself including time focusing on the key issues of content validity, psychometric evidence for validity and reliability, and interpretation of scores. The second part of the workshop will move on to look at strategies for documenting PRO evidence in the wider context of the clinical trial evidence including endpoint models and PRO components of the statistical analysis plan. The workshop will finish by examining how to address PRO instrument modification both in terms of linguistic validation and ePRO adaptation. Because a standard and well-organized PRO Evidence Dossier to support labeling and promotional claims for FDA and EMA regulated medical products is critical, increases efficiency of providing relevant PRO information to the regulatory agencies and increases efficiency of the regulatory review process of the PRO information, participants will be introduced to the 'When', 'What', and 'How' of a PRO Evidence Dossier. The workshop will finish with discussons on conducting a gap analysis and on when to engage regulatory agencies to discuss the PRO endpoint(s). Throughout, strategies for maximizing opportunities for achieving a PRO label claim will be highlighted and discussed within the group. The workshop will include an example claim and corresponding PRO instrument to work through as a class. Level: Basic

#### Workshop 13

St. James Room

Advanced Psychometric Methods, Part 2: Executing and Interpreting Exploratory and Confirmatory Instructors: Donald Stull, PhD, United BioSource Corporation, Bethesda, MD, USA; Margaret Vernon, PhD, United BioSource Corporation, Bethesda, MD, USA and Elizabeth Merikle, PhD, United BioSource Corporation, Bethesda, MD, USA

This half-day workshop will build on Advanced Psychometric Methods, Part 1, by presenting results from examples of exploratory and confirmatory factor analyses; executing live, interactive analyses; and interpreting results of output, particularly for confirmatory factor analyses and structural equation models (including latent growth mixture models). We will work through examples of analyses by presenting hypothesized models, discussing key analytic criteria (e.g., sample size, factor loading size, extraction, rotation, key parameter estimates, cross-loadings and correlated errors, model specification and identification, fit indices, indications of model misfit), and how to interpret output. Annotated examples will be presented from output from selected software (e.g., SAS, Stata, EQS, and Mplus), but the issues are relevant regardless of the users software. Level: Advanced

#### Workshop 14

Chelsea/Richmond Room

Systematic Reviews of Measurement Instruments

Instructors: Caroline Terwee, PhD, VU University Medical Center, Amsterdam, the Netherlands; Lidwine Mokkink, PhD, VU University Medical Center, Amsterdam, the Netherlands; Henrica de Vet, PhD, VU University Medical Center, Amsterdam, the Netherlands and Donald Patrick, PhD, University of Washington, Seattle, Washington, USA

Systematic reviews of measurement instruments are reviews in which the measurement properties of all available instruments that measure a specific construct are systematically appraised and compared according to quality standards. Considering the large number of instruments available in many fields, such reviews are becoming increasingly important for choosing instruments for different applications. They can also aid to minimize the number of instruments used in a field by recommending a selection of best or the most promising instruments. Finally, systematic reviews are important for detecting gaps in knowledge on measurement properties and prioritizing new validation studies. The number of systematic reviews of measurement properties is increasing rapidly. However, the methodology and quality of such reviews varies widely, with regard to the search strategy, quality assessment of the included studies, and pooling and interpretation of the results. In this workshop we provide guidelines and practical tools for performing high quality systematic reviews of measurement instruments. Our methodology closely resembles the methodology of the Cochrane Collaboration for systematic reviews of randomized trials. Level: Basic

#### Workshop 15

Cadogan Room

Innovative Methods for Electronically Capturing Patient-Reported Outcomes and Preference Data in Non-Interventional Studies

Instructors: Ingela Wiklund, PhD, United BioSource Corporation, London, United Kingdom; Karin Coyne, PhD United BioSource Corporation, Bethesda, MD, USA and Shae Wilkins, Arrowhead Electronic Healthcare, Austin, TX, USA

The increasing use of ePROs in a range of clinical and research settings has created opportunities to measure patient experience in innovative ways. This workshop focuses on best practices for leveraging electronic data collection methods to improve data quality and streamline capture of data in non-interventional studies. This workshop will draw from a range of examples from the literature, the field, and experience with the EXACT-PRO Initiative to inform a discussion of key issues associated with ePRO development and implementation. Specific topics to be addressed include: an overview of technology currently in use, new instrument development using electronic platforms innovatively and considerations for migrating existing validated instruments from paper to electronic platforms. The workshop will also address the use of technology to improve the administration of preference assessment methods including utilities, time trade-off and conjoint analysis. Other important topics include compliance enhancement strategies, and use of electronic methods with special populations such as older adults and children. *Level: Basic* 

#### Workshop 16

Regents Room

DERIVING QUALITY ADJUSTED LIFE YEARS FROM PATIENT REPORTED OUTCOME MEASURES: METHODS FOR DEVELOPING PREFERENCE-BASED MEASURES OF HEALTH FROM EXISTING MEASURES

Instructors: Tracey Young, PhD, University of Sheffield, Sheffield, South Yorkshire, UK; John Brazier, PhD, University of Sheffield, Sheffield, South Yorkshire, UK and Donna Rowen, PhD, University of Sheffield, South Yorkshire, UK

Recent years has seen increasing reliance on a few generic preference-based measures of health (e.g. EQ-5D, HUI3, QWB or SF-6D) for calculating Quality Adjusted Life Years (QALYs) for economic evaluation. However, generics measures may not be used in key clinical studies. This may be due to a desire to reduce patient burden or a view that generic instruments are not valid for the condition or responsive to the effects of treatment. For these reasons there is interest in developing new preference-based measures of health. This workshop focuses on the estimation of the preference-based indices from existing generic and condition specific measures of health related quality of life. The focus is on the derivation of health states from existing measures rather than the other stages of valuing a sample of states and modeling the health state values. The workshop offers a practical introduction to the use of psychometric methods in the development and refinement of health state classifications. It will also examine the policy implications of using different descriptive systems to derive preference-based measures. It assumes a basic knowledge of HRQoL measurement and QALYs. Level: Advanced

4:30 – 5:30 pm

#### Mentor/Mentee Session

Windsor Room

Individuals who have registered for this program are invited to attend this event. If you would like to participate, but have not registered, please visit the ISOQOL Registration Desk to determine availability in the program.

5:30 - 7:00 pm

#### **Welcome Reception**

Balmoral Room

Join with your friends and colleagues at this informal get-together to begin the conference.

7:00 – 8:30 pm

Getting G Theory to Work for You

Room **Chair:** 

Speaker: Geoff Norman, PhD, McMaster University, Canada

#### Thursday, October 28, 2010

7:00 am - 5:00 pm

**Registration and Exhibits** 

West Wing Lobby

A continental breakfast will be served at 7:30 am. Please be sure to visit the exhibits!

8:00 am - 6:45 pm

Poster Session I on Display

Viscount Suite and Foyer

Poster numbers 1 through 104 are on display today (see page 36 through 42)

7:45 - 8:00 am

Welcome/Remarks

Room

Conference Chairs: Stefan Cano, PhD and Jane Scott, PhD

ISOQOL President: Diane Fairclough, DrPH

8:00 - 9:30 am

**Plenary Session:** 

Psychometric Methods for Developing and Evaluating Rating Scales: Why I Do What I Do

sponsored by ??

Chairs: Jeremy Hobart, PhD and Stefan Cano, PhD

Speakers:

Sandringham Suite

Although classical test theory, generalizability theory and modern psychometrics (including Rasch analysis and IRT) are commonly discussed in ISOQOL meetings and publications in our journal, Quality of Life Research, the appropriate use of these different methods has not been discussed in a major forum within ISOQOL. To allow members to learn about the strengths and appropriate use of each of these models for psychometric analysis, session chairs Jeremy Hobart and Stefan Cano will lead what promises to be a lively session with some of the world's experts in each of these methods answering the question "Why I Do What I Do".

OR?

Rating scales play a critical role in shaping health care and health outcomes. Several psychometric methods are used to develop and validate health rating scales. Each has its strengths and no method is fully adequate to address all the requirements of rigorous psychometric validation. Session chairs Jeremy Hobart and Stefan Cano invite experts in each of these methods to present and discuss "Why I Do What I Do". Invited speakers include leaders in the application of the following methods to patient reported outcome data:

- Generalizability Theory
- Item Response Theory
- Rasch Measurement

9:30 - 9:45 am

**Break** 

West Wing Lobby

9:45 – 11:15 am

**Concurrent Oral Sessions** 

Mixed Methodology Chair: Karen Sousa, PhD

Sandringham Suite

1713/What do people with dementia and their proxies say about HRQL? A quantitative test of qualitative findings

Sarah C. Smith, Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, UK, Brendan Mulhern, John E. Brazier, School of Health and Related Research, University of Sheffield, Sheffield, UK, Donna L. Lamping, Department of Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, UK, Martin Knapp,

London School of Economics & Political Science, University of London, London, UK, Donna Rowen, School of Health and Related Research, University of Sheffield, Sheffield, UK, Vanessa Loftus, Sube Banerjee, Institute of Psychiatry, Kings College London, London, UK

#### 1730/Validity in fatigue measurement: complementing quality and quantity

Stefan J. Cano, Jeremy C. Hobart, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, Devon, UK

#### 1640/The benefits of mixed methods in scale development II: Selecting optimal mode of administration

Claudia Gorecki, Clinical Trials Research Unit, University of Leeds, Leeds, West Yorkshire, UK, Jane Nixon, Clinical Trials Research Unit, University of Leeds, Leeds, West Yorkshire, United Kingdom, Donna L. Lamping, Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, United Kingdom, Julia M. Brown, Clinical Trials Research Unit, University of Leeds, Leeds, West Yorkshire, United Kingdom, Stefan Cano, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, United Kingdom

#### Responsiveness I

Chair: John Broderson, PhD Hilton Meeting Rooms 1-6

### 1572/Responsiveness and Minimal Important Differences in EORTC QLQ-C30, EQ-5D and 15D in patients with multiple myeloma - A prospective study

Ann Kristin Kvam, Haematology, Oslo University Hospital, Oslo, Norway, Peter Fayers, Applied Health Sciences, University of Aberdeen, Scotland, Finn Wisløff, Medicine, University of Oslo, Oslo, Norway

#### 1483/Minimally important differences for six PROMIS-Cancer scales

Kathleen J. Yost, David T. Eton, Health Sciences Research, Mayo Clinic, Rochester, MN, Sofia F. Garcia, David Cella, Medical Social Sciences, Northwestern University, Feinberg School of Medicine, Chicago, IL

### 1294/Minimal important difference for individual subjects and groups of subjects - why the two cases should be distinguished

Georg Kemmler, Johannes Giesinger, Lisa Wintner, Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Tyrol, Austria, Hubert Denz, Internal Medicine, Natters State Hospital, Innsbruck, Tyrol, Austria, Bernhard Holzner, Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Tyrol, Austria

### 1487/Using Multiple Anchor and Distribution-based Estimates to Determine the Minimal Important Difference (MID) for the Urticaria Activity Score (UAS)

Susan D. Mathias, Outcomes Research, Health Outcomes Solutions, Winter Park, FL, Ross D. Crosby, Biomedical Statistics & Methodology, Neuropsychiatric Research Institute, Fargo, ND, James Zazzali, Health Economics & Outcomes Research, Genentech Inc, S San Francisco, CA

#### **Pediatrics**

Chair: Anne Klassen, DPhil

Balmoral Suite

### 1237/Assessing The Impact Of Musculoskeletal Impairment On Children's Quality Of Life In Malawi: Identifying The Concepts For Evaluation

Yasmene Alavi, Infectious and Tropical Disease, London School of Hygiene & Tropical Medicine, London, UK, Vincent Jumbe, College of Medicine, University of Malawi, Blantyre, Malawi, Sally Hartley, School of Allied Health Professions, University of East Anglia, Norwich, UK, Sarah Smith, Donna Lamping, Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, UK, Christopher Lavy, Nuffield Department of Orthopaedic Surgery, Oxford University, Oxford, UK

#### 1511/Predictors of Health Related Quality of Life of adolescents with Type 1 Diabetes

Tatiana S. Novato, Sonia A. Grossi, Medical Surgical Nursing, University of São Paulo, São Paulo, São Paulo, Brazil, Balduino Tschiedel, Márcia K. Coutinho, Silvana E. Speggiorin, Ana M. Ferreira, Institute for Children With Diabetes, Nossa Senhora da Conceição Hospital, Porto Alegre, Rio Grande do Sul, Brazil

#### 1786/On relationships of fatigue, quality of life and family impact among children with live-limiting illnesses

I-Chan Huang, Mary Anderson, Epidemiology and Health Policy Research, Sanjeev Tuli, John Nackashi, Pediatrics, University of Florida, Gainesville, FL, Dennis Revicki, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD, Elizabeth Shenkman, Epidemiology and Health Policy Research, University of Florida, Gainesville, MD

### 1704/Testing the Item Response Theory properties of the KIDSCREEN-10 HRQOL Index in school-children from 15 European countries

Ulrike Ravens-Sieberer, Veronika Ottova, Michael Erhart, Child Public Health, University Medical Center Hamburg-Eppendorf, Hamburg, Hamburg, Germany

Oncology I

Chair: Juan Dapueto, MD

Sovereigh Suite

#### 1533/Adapting existing HRQOL measures for use in routine oncology clinical practice

Clare Harley, Elena Takeuchi, Sally Taylor, Kate Absolom, Lyndsay Campbell, Sookhoe Eng, Galina Velikova, Oncology, University of Leeds, Leeds, West Yorkshire, UK

#### 1404/Conceptual Model of Quality of Life in Sarcoidosis

Willemien de Kleijn, Jolanda De Vries, Medical Psychology, Tilburg University, Tilburg, the Netherlands

### 1711/Measuring the Symptom Burden of Lung Cancer: The Validity and Utility of the Lung Cancer Module of the M. D. Anderson Symptom Inventory (MDASI-LC)

Tito R. Mendoza, Xin Shelley Wang, Guadalupe Palos, Symptom Research, Charles Lu, Thoracic/Head and Neck Medical Oncology, Zhongxing Liao, Radiation Oncology, Gary Mobley, Symptom Research, University of Texas M.D. Anderson Cancer Center, Houston, Texas, Shitij Kapoor, Psychiatry and Behavioral Sciences, University of Texas Medical School at Houston, Houston, Texas, Charles S. Cleeland, Symptom Research, University of Texas M.D. Anderson Cancer Center, Houston, Texas

#### 1762/Towards a Modeling of Health-Related Quality of Life in People with Advanced Cancer

Ana Maria Rodriguez, Rehabilitation Sciences, Clinical Epidemiology, Bruno Gagnon, Medicine and Oncology, Faculty of Medicine, McGill University, Montreal, Quebec, Canada, Nancy E. Mayo, Division of Clinical Epidemiology, McGill University, Royal Victoria Hospital, Montreal, Quebec, Canada

11:15 – 11:30 am **Break** *West Wing Lobby* 

11:30 am – 1:00 pm Concurrent Oral Sessions

Analysis Issues Chair: Madeleine King, PhD Sandringham Suite

### 1189/Time to deterioration of quality of life score as a modality of longitudinal analysis in patients with breast cancer

Zeinab Hamidou, Biostatistics and Epidemiology, Centre Georges François Leclerc, Dijon, France, Tienham S. Dabakuyo, Biostatistics and Epidemiology, CGFL, Dijon, France, Mariette Mercier, Pharmacy, University of Franche-comté, Besançon, France, Jean Fraisse, Surgery, CGFL, Dijon, France, Sylvain Causeret, Surgery, CGFL, Dijon, 21079, Hervé Tixier, Marie-Martine Padeano, Catherine Loustalot, Jean Cuisenier, Surgery, CGFL, Dijon, France, Jean-Marc Sauzedde, Surgery, Val de Saône private hospital, Mâcon, France, M. Smail, surgery, Sainte Marie private hospital, Chalon Sur Saône, France, Jean-Philibert Combier, Patrick Chevillote, Christian Rosburger, Surgery, Hôtel-Dieu hospital, Le Creusot, France, Patrick Arveux, Franck Bonnetain, Biostatistics and Epidemiology, CGFL, Dijon, France

### 1195/Tracking a Symptom Cluster over Time in Transplant Patients: Detecting Patterns of Response to Treatment Using Latent Class Growth Analysis

Cynthia R. Gross, Pharmacy, Olga Gurvich, Nursing, University of Minnesota, Minneapolis, MN

#### 1369/Effect of Time Windows in Analysis of Health-Related Quality of Life (HRQOL) Outcomes

John T. Maringwa, Corneel Coens, Chantal Quinten, Francesca Martinelli, Quality of Life, EORTC, Brussels, Belgium, Jolie Ringash, The Princess Margaret Hospital, University of Toronto, Toronto, Canada, David Osoba, Quality of Life Consulting, Quality of life Consulting, West Vancourver, Canada, Bryce B. Reeve, Division of Cancer Control & Population Studies, National Cancer Institute, NIH, Bethesda, Madeleine King, PoCoG, University of Sydney, Sydney, Australia, Charles S. Cleeland, Symptom Research, University of Texas, Houston, Henning Flechtner, Medical Faculty, Otto-von-Guericke University, Magdeburg, Germany, Carolyn Gotay, Primary Prevention, School of Population and Public Health, Vancouver, Canada, Eva Greimel, Obstetrics and Gynecology, Medical University Graz, Graz, Austria, Martin J. Taphoorn, Neurology, VU Medical Center, Amsterdam, Netherlands, Joseph Schumucker-von Koch, Medical Ethics, University of Regensburg, Regensburg, Germany, Joachim Weis, Tumor Biology Center, University of Freiburg, Freiburg, Germany, Egbert F. Smit, Pulmonary Diseases, Vrije Universiteit VUMC, Amsterdam, Netherlands, Jan P. van Meerbeeck, Thoracale Oncologie, Universitair Ziekenhuis Gent, Gent, Belgium, Andrew Bottomley, Quality of Life, EORTC, Brussels, Belgium

### 1714/Longitudinal data with follow-up truncated by death: Matching statistical analysis to research, clinical and policy aims

Laura L. Johnson, NCCAM, US National Institutes of Health, Bethesda, MD, Brenda F. Kurland, Clinical Statistics, Fred Hutchinson

Cancer Research Center, Seattle, WA, Brian L. Egleston, Biostatistics and Bioinformatics, Fox Chase Cancer Center, Philadelphia, PA, Paula Diehr, Biostatistics and Health Services, University of Washington, Seattle, WA

Economic Evaluation I Chair: David Feeny, PhD

Sovereign Suite

1727/Item Identification for the EXACT-U: A Preference-Based Measure to Report Utilities for COPD Exacerbations
Jennifer M. Petrillo, John Cairns, Donna L. Lamping, Health Services Research and Policy, London School of Hygiene & Tropical
Medicine, London, UK, Paul W. Jones, Clinical Science, St George's, University of London, UK

### 1356/Modelling the cost-utility of screening programmes for diabetic retinopathy in India: estimating utility values

Sarah Polack, Yasmene Alavi, Infectious and Tropical Diseases, London School of Hygiene & Tropical Medicine, London, UK, Rachapalle R. Sudhir, Vaitheeswaran Kulothungan, Preventive Ophthalmology, Sankara Nethralaya Eye Hospital, Chennai, India, Hannah Kuper, Non-communicable Disease Epidemiology Unit, London School of Hygiene & Tropical Medicine, London, UK

### 1275/Estimating a Multi-Attribute Utility Function for the Health Utilities Index Mark 3 System Based on the Preferences of Singaporeans

Nan Luo, Epidemiology and Public Health, Hwee-Lin Wee, Pharmacy, National University of Singapore, Center for Health Research, Kaiser Permanente Northwest, Portland, OR, Kok-Yong Fong, Rheumatology and Immunology, Singapore General Hospital, Singapore, Singapore, Shu-Chuen Li, School of Biomedical Sciences and Pharmacy, University of Newcastle, Callaghan, Australia, Mandy Ow, Pharmacy, National University of Singapore, Singapore, Singapore, David Machin, School of Health and Related Sciences, University of Sheffield, Dorset, UK, Julian Thumboo, Rheumatology and Immunology, Singapore General Hospital, Singapore, Singapore

1582/Beyond economic evaluation: An appropriate scoring system for EQ-5D based on real values for health Paul Kind, Centre for Health Economics, University of York, York, UK

**Mental Health** 

Chair: Cindy Lam, MD

Balmoral Suite

#### 1379/Impact of Transdiagnostic Symptoms in the Measurement of Depression using the PHQ-9

Karon F. Cook, Rehabilitation Medicine, University of Washington, Seattle, Houston, TX, Charles Bombardier, Rehabilitation Medicine, Jesse R. Fann, Psychiatry & Behavioral Sciences, University of Washington, Seattle, Seattle, WA, Kurt Kroenke, Medicine, Indiana University School of Medicine, Indianapolis, IN

#### 1427/Longitudinal Course of Depression Symptoms in Multiple Sclerosis

Dagmar Amtmann, Rehabilitation Medicine, University of Washington, Seattle, WA, Karon Cook, Rehabilitation Medicine, University of Washington, Houston, TX, Kurt L. Johnson, Dawn M. Ehde, Charles H. Bombardier, Nina C. Lang, Rehabilitation Medicine, University of Washington, Seattle, WA

#### 1643/Screening for Major Depression Episode with the SF-12v1 in 6 European countries.

Gemma Vilagut, Carlos G Forero, Núria Ortega, Health Services Research Group, Institut Municipal d'Investigació Mèdica, Barcelona, Spain, Ronny Bruffaerts, Department of Neurosciences, University Hospitals Gasthuisberg, Leuven, Belgium, Giovanni de Girolamo, IRCCS Fatebenefratelli, Berscia, Italy, Ron de Graaf, Program Epidemiology, Trimbos Institute, Utrecht, The Netherlands, Josep Maria HAro, Research and Development Unit, Parc Sanitari Sant Joan de Deu, Sant Boi de Llobregat, Spain, Vivianne Kovess, Dpt Epidemiologie, EHESP, Paris, France, Herbert Matschinger, Department of Psychiatry, University of Leipzig, Leipzig, Germany, Jordi Alonso, Health Services Research Group, Institut Municipal d'Investigació Mèdica, Barcelona, Spain

### 1355/Long-Term Health Related Quality of Life and Psychological Well-Being Outcomes in Rectal Cancer Patients Treated with Preoperative Chemoradiotherapy

Samantha Serpentini, Clinica Chirurgica II, Ospedale/Università di Padova, Padova, Italy, Paola Del Bianco, Sperimentazioni Cliniche e Biostatistica, Istituto Oncologico Veneto, Padova, Italy, Paola Toppan, Clinica Chirurgica II, Ospedale/Università di Padova, Padova, Italy, Paola Zotti, Attività Clinico-Specialistica e di Supporto, Istituto Nazionale dei Tumori CRO, Aviano, Italy, Antonino De Paoli, Oncologia Radioterapica e Diagnostica per Immagini, Istituto Nazionale Tumori, CRO, Aviano, Italy, Carlo Capirci, Radioterapia, Azienda ULSS 18, Rovigo, Italy, Antonio Amato, Unità di ColonProctologia, Presidio Ospedaliero di Sanremo, Sanremo, Italy, Elisa Alducci, Clinica Chirurgica II, Ospedale/Università di Padova, Padova, 35128, Gian L. De Salvo, Sperimentazioni Cliniche e Biostatistica, Istituto Oncologico Veneto, Padova, Italy, Salvatore Pucciarelli, Clinica Chirurgica II, Ospedale/Università di Padova, Padova, Italy

#### **Qualitative Methods**

Chair: Linda Abetz-Webb, MA

Hilton Meeting Rooms 1-6

#### 1375/Voice Outcomes in Head and Neck Cancer - What Matters to Patients?

Elaine McColl, Newcastle Clinical Trials Unit, Newcastle University, Newcastle upon Tyne, UK, Jo Patterson, Speech and Language Therapy, City Hospitals Sunderland NHS Foundation Trust, Sunderland, United Kingdom, Vinidh Paleri, Otolaryngology-Head and Neck Surgery, The Newcastle upon Tyne Hospitals NHS Trust, Newcastle upon Tyne, United Kingdom

### 1666/Understanding Perspectives of Adults with Sickle Cell Disease in Developing a Disease Specific Quality of Life Measurement System

Marsha J. Treadwell, Hematology/Oncology, Children's Hospital & Research Center Oakland, Oakland, CA, Roger Levine, American Institutes for Research, San Mateo, CA, San Keller, American Institutes for Research, Chapel Hill, NC, Kathryn Hassell, Sickle Cell Treatment and Research Center, University of Colorado, Denver, CO, Ellen Werner, Blood Diseases and Resources, National Heart, Lung and Blood Institute, Bethesda, MD

### 1368/Evidence-based management of uncertainty in rheumatic conditions: Comparing views of health care professionals and patients

Sophie Cleanthous, Unit of Behavioural Medicine, University College London, London, UK, Michael Shipley, David Isenberg, Centre for Rheumatology, Stanton Newman, Unit of Behavioural Medicine, University College London Hospital, London, UK, Stefan Cano, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, UK

### 1612/Exploring needs-based quality of life (QoL) from the perspective of the individual with Post Polio Syndrome (PPS): A thematic analysis

Anne-Marie C. Quincey, Clinical Trials Unit, Walton Centre for Neurology and Neurosurgery, Fazakerley, Liverpool, UK, Samantha M. Wong, Clinical Trials Unit, Carolyn A. Young, Neurology, Walton Centre for Neurology and Neurosurgery, Fazakerley, Liverpool, England

#### 1:00 - 2:00 pm

Lunch on Your Own | SIG Meetings | Committee Meetings

IRT SIG QoL in Clinical Practice SIG Industry Advisory Committee Governance Committee York Room Lancaster Room Hilton Meeting Room 7 4th Floor Presentation Room

#### 2:00 - 3:30 pm

**Concurrent Symposia** 

Invited Symposium: RATING SCALE VALIDITY: ITS CRITICAL IMPORTANCE AND HOW WE ACHEIVE IT

Chair: ???

Sandrigham Suite

#### **NEED TALK TITLES**

### Symposium 1430: DEVELOPMENT AND COMPARISONS OF ALTERNATIVE PREFERENCE-BASED MEASURES OF HEALTH

Chair: Stephen B. Clauser, PhD

Sovereign Suite

#### Individual Abstract 1433

DEVELOPING PREFERENCE-BASED MEASURES FROM EXISTING QUALITY OF LIFE MEASURES: WHY, HOW AND SHOULD WE?

John Brazier, School of Health and Related Research, Sheffield, South Yorkshire, UK

#### **Individual Abstract 1434**

FLOORS, CEILINGS, AND FOUNDATIONS: COMPARISONS AMONG GENERIC PREFERENCE-BASED MEASURES

David Feeny, Center for Health Research, Kaiser Permanente Northwest, Portland, OR, USA

#### **Individual Abstract 1702**

HEALTH PREFERENCE ASSESSMENT IN THE PROMIS PROJECT: ESTIMATION AND VARIATION IN PREFERENCE SCORES BY DEMOGRPHIC AND DISEASE GROUPS

Dennis A. Revicki, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD, USA

### Individual Abstract 1721 PROCEEDING WITH CARE

Paul Kind, Centre for Health Economics, University of York, UK

### Symposium 1812: RECENT ADVANCES IN THE GENETIC UNDERPINNINGS OF QOL FROM THE GENEQOL CONSORTIUM

Chair: Jeff Sloan, PhD

Balmoral Suite

#### Individual Abstract 1210

### GENES SELECTED FOR THEIR RELEVANCE TO PAIN ARE ALSO ASSOCIATED WITH FATIGUE AND DYSPNEA: EVIDENCE OF THE EUROPEAN PHARMACOGENETIC OPIOID STUDY

Ailko H. Zwinderman, Medical Epidemiology and Biostatistics, Mirjam A. Sprangers, Medical Psychology, Frank Baas, Neurogenetics, Cornelis J. Van Noorden, Cell Biology and Histology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands, Lukas Radbruch, Palliative Medicine, University Clinic, Aachen, Germany, Andrew Davies, Palliative Medicine, Royal Marsden NHS Foundation Trust, Sutton, United Kingdom, Dick F. Swaab, -, Netherlands Institute for Neuroscience, Amsterdam, Netherlands, Jeff Sloan, Health Sciences Research, Mayo Clinic, Rochester, MN, Stein Kaasa, Intensive Care Medicine, Frank Skorpen, Laboratory Medicine, Pal Klepstad, Intensive Care Medicine, Norwegian University of Science and Technology, Trondheim, Norway

#### **Individual Abstract 1585**

### A GENETIC LINK TO QOL: THE RELATIONSHIP BETWEEN CYTOKINE GENE SINGLE NUCLEOTIDE POLYMORPHISMS AND SYMPTOM BURDEN AND QUALITY OF LIFE IN LUNG CANCER SURVIVORS

Sarah M. Rausch, Health Outcomes and Behavior, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL, Matthew M. Clark, Christi Patten, Psychiatry and Psychology, Jeff Sloan, Biostatistics, Ping Yang, Epidemiology, Mayo Clinic, Rochester, MN

#### **Individual Abstract 1777**

### EXPANSION OF THE WILSON & CLEARY THEORETICAL MODEL TO INCORPORATE GENETIC INFLUENCES ON QUALITY OF LIFE

Jeff Sloan, Health Sciences Research, Mayo Clinic, Rochester, MN, Mirjam Sprangers, Psychology, Amsterdam Medical Center, Amsterdam, Netherlands

# Symposium 1173: METHODOLOGICAL ADVANCES IN INTERPRETING CHANGE: A HEAD-TO-HEAD COMPARISON OF RESPONSE SHIFT ASSESSMENT IN A NATIONAL SAMPLE OF MULTIPLE SCLEROSIS PATIENTS

Chair: Carolyn Schwartz, ScD Hilton Meeting Rooms 1-6

#### Individual Abstract 1177

#### DIFFERENTIAL ITEM FUNCTIONING OVER TIME AS A PRELIMINARY RESPONSE SHIFT DETECTION METHOD

Carolyn E. Schwartz, Medicine and Orthopaedic Surgery, DeltaQuest Fdn and Tufts U School of Medicine, Concord, MA, Rita Bode, Center for Rehabilitation Outcome Research, Feinberg School of Medicine

#### **Individual Abstract 1178**

### USING STRUCTURAL EQUATION MODELING TO DETECT RESPONSE SHIFT IN PERFORMANCE AND QOL SCORES OF MULTIPLE SCLEROSIS PATIENTS

Belinda L. King-Kallimanis, Medical Psychology, University of Amsterdam, Amsterdam, The Netherlands, Frans J. Oort, Education, Faculty of Social and Behavioural Science, University of Amsterdam, Sandra Nolte, Association of Dermatological Prevention, Carolyn E. Schwartz, Medicine and Orthopaedic Surgery, DeltaQuest Fdn and Tufts U School of Medicine, Mirjam A. Sprangers, Medical Psychology, University of Amsterdam

#### **Individual Abstract 1179**

#### LATENT TRAJECTORY ANALYSIS DID NOT DETECT RESPONSE SHIFT IN GENERAL HEALTH AMONG MS PATIENTS

Sara Ahmed, School of Physical and Occupational Therapy, McGill University, Montreal, QC, CANADA, Nancy Mayo, Susan Scott, Ayse Kuspinar, Stanley Hum, Medicine, School of Physical and Occupational Therap, McGill University, Carolyn E. Schwartz, Medicine and Orthopaedic Surgery, DeltaQuest Fdn and Tufts U School of Medicine

#### Individual Abstract 1180

### USING CLASSIFICATION AND REGRESSION TREE TO EXAMINE EVIDENCE OF QUALITY OF LIFE RESPONSE SHIFT IN PATIENTS WITH MULTIPLE SCLEROSIS

Yuelin Li, Behavioral Science, Memorial Sloan Kettering Cancer Center, New York, NY, Carolyn E. Schwartz, Medicine and Orthopaedic Surgery, DeltaQuest Fdn and Tufts U School of Medicine

3:30 – 3:45 pm **Break** *West Wing Lobby* 

3:45 – 5:15 pm

**Concurrent Oral Sessions** 

#### Scale Selection

Chair: Cindy Gross, PhD Hilton Meeting Rooms 1-6

#### 1207/Reaching the right decision: Proposal of a scale selection strategy in stroke research

Karen Baker, Brain Repair and Rehabilitation, UCL Institute of Neurology, London, UK, E Diane Playford, Brain Repair and Rehabilation, UCL Institute of Neurology, London, UK, Stefan J. Cano, Clinical Neurology, Peninsula Medical School, Plymouth, UK

#### 1205/Selecting patient reported outcomes in glaucoma studies: which instrument?

Jemaima Che Hamzah, Health Services Research Unit, University of Aberdeen, Aberdeen, Scotland, UK, Jennifer M. Burr, Craig R. Ramsay, Augusto Azuara-Blanco, Maria Prior, for Glaucoma Screening Platform Study (GPS), Health Services Research Unit, University of Aberdeen, Aberdeen, Scotland, United Kingdom

#### 1228/The need for a new Hepatitis C Virus-Specific Health-Related Quality of Life measure

Martin Duracinsky, Andrew R. Armstrong, Christophe Lalanne, Olivier Chassany, Department of Clinical Research and Development, Assistance Publique-Hopitaux de Paris, Paris, France

### 1018/Inter-rater Reliability of the COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) Checklist

Lidwine B. Mokkink, Epidemiology & Biostatistics, EMGO Institute for Heealth and Care Research, VUmc, Amsterdam, Netherlands, Caroline B. Terwee, Epidemiology & Biostatistics, EMGO Institute for Health and Care Research, VUmc, Amsterdam, Netherlands, Elizabeth Gibbons, Public Health, Patient-reported Outcome Measurement, University of Oxford, Oxford, UK, Paul W. Stratford, School of Rehabilitation Science, Clinical Epidemiol, McMaster University, Hamilton, Canada, Jordi Alonso, Health Services Research Unit, IMIM-Hospital del Mar, CIBERESP, Barcelona, Spain, Donald L. Patrick, Health Services, University of Washington, Seattle, Washington, Dirk L. Knol, Epidemiology and Biostatistics, EMGO Institute for Health and Care Research, VUmc, Amsterdam, Netherlands, Henrica C. De Vet, Epidemiology and Biostatistics, EMGO Institute for Heealth and Care Research, VUmc, Amsterdam, Netherlands

### Geriatrics & End of Life Chair: Sara Ahmed, PhD

Sovereign Suite

#### 1120/Enjoying Old Age: Perceptions of Older Adults Regarding Quality of Life

Sofia v. Humboldt, Isabel P. Leal, Research Unit in Psychology and Health, I&D, Instituto Superior de Psicologia Aplicada (ISPA), Lisboa, Portugal

#### 1101/Improving quality of care in geriatrics, Sweden

Ewa Wressle, Geriatrics, Linköping University, Linköping, Sweden

### 1435/Quality of Life of Elders with Dementia and Their Caregivers: Use of Multiple Measures for Community-Based Translational Research

Betty S. Black, Deirdre M. Johnston, Peter V. Rabins, Constantine G. Lyketsos, Quincy M. Samus, Psychiatry & Behavioral Sciences, Johns Hopkins University, Baltimore, MD

#### 1242/Health, attitudes to ageing and quality of life across cultures

Gail Low, Anita E. Molzahn, Donald Schopflocher, Nursing, University of Alberta, Edmonton, Alberta, Canada

#### **Fatique**

Chair: Jane Scott, PhD

Balmoral Suite

#### 1339/Malaise/weakness/fatigue a relevant symptom cluster for persons living with HIV: maybe, maybe not

Karen H. Sousa, Nursing, University of Colorado, Aurora, Colorado, Soyoung Lee, Psychology, Arizona State University, Tempe, Arizona

1681/Exploring fatigue from the perspective of the individual with Post Polio Syndrome (PPS): A thematic analysis Samantha M. Wong, Clinical Trials Unit, Anne-Marie C. Quincey, Clincial Trials Unit, Carolyn A. Young, Neurology, Walton Centre

for Neurology and Neurosurgery, Fazakerley, Liverpool, UK

#### 1575/Symptom burden in chronic myeloid leukemia survivors treated with Imatinib.

Fabio Efficace, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy, Massimo Breccia, Hematology, University of Rome La Sapienza, Rome, Italy, Michele Baccarani, Hematology-Oncology, University of Bologna, Bologna, Italy, Giuliana Alimena, Hematology, University of Rome La Sapienza, Rome, Italy, Giorgio Lambertenghi Deliliers, Hematology, University of Milan, Milan, Italy, Giorgina Specchia, Hematology, University of Bari, Bari, Italy, Francesco Cottone, Marco Vignetti, Franco Mandelli, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy

# 1117/A Randomized Clinical Trial of Cognitive Behavioral Therapy and Physical Exercise to Reduce Climacteric Symptoms and Improve Health-Related Quality of Life in Breast Cancer Patients Experiencing Treatment-Induced Menopause: Short-Term Results

Neil K. Aaronson, Saskia F. Duijts, Psychosocial Research & Epidemiology, Hester S. Oldenburg, Surgery, Marc van Beurden, Gynecology, The Netherlands Cancer Institute, Amsterdam, The Netherlands

Validity

Chair: Stefan Cano, PhD

Sandringham Suite

#### 1302/Dignity and the content validity of the Patient Dignity Inventory

Gwenda Albers, H Roeline W. Pasman, Mette L. Rurup, Department of Public and Occupational Health, Henrica C W. de Vet, Department of Epidemiology and Biostatistics, Bregje D. Onwuteaka-Philipsen, Department of Public and Occupational Health, EMGO Institute for Health and Care Research, Amsterdam, The Netherlands

### 1595/Construct validity of the ThyPRO assessed by multiple groups confirmatory factor analysis in patients with thyroid diseases

Torquil Watt, Medical Endocrinology, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark, Mogens Groenvold, Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark, Aase K. Rasmussen, Ulla Feldt-Rasmussen, Medical Endocrinology, Copenhagen University Hospital Rigshospitalet, Copenhagen, Denmark, Laszlo Hegedus, Steen J. Bonnema, Endocrinology and Metabolism, Odense University Hospital, Odense, Denmark, Jabob B. Bjorner, National Research Centre for the Working Environment, Copenhagen, Denmark

### 1426/Use of Structural Equation Modeling to Test the Construct Validity of the Iranian SF-12 Health Survey Version 2 (SF-12v2).

Camelia Rohani, Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Stockholm, Sweden, Heidar-Ali Abedi, Nursing, Isfahan University of Medical Sciences, Isfahan, Iran, Ann Langius-Eklöf, Health & Medical Sciences, Örebro University, Örebro, Sweden

#### 1213/Content validity of utility assessments in Type 2 Diabetes and Alzheimer's Disease

Clare McGrath, Pfizer, Tadsworth, Surrey, UK, Diana Rofail, Linda Abetz, Mapi Values, Bollington, Cheshire, United Kingdom

5:15 – 6:45 pm

Reception and Meet the Author Poster Session

Viscount Suite and Foyer

6:45 pm

SIG Meeting | Committee Meeting

6:45 – 7:45 pm

**Fundraising Committee** 

York Room

6:45 - 8:15 pm

TCA SIG

Balmoral Suite

#### Friday, October 29, 2010

7:00 am - 5:00 pm

#### Registration and Exhibits

West Wing Lobby

A continental breakfast will be served at 7:00 am. Please be sure to visit the exhibits!

7:45 - 8:00 am

President's Address

Diane Fairclough, DrPH, University of Colorado, Denver, CO, USA

Sandringham Suite

8:00 - 9:30 am

**Plenary Session:** 

The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities

sponsored by: Pfizer

Chair: Professor Richard Lilford, Clinical Epidemiology, University of Birmingham, UK

Speakers: Nick Black, MD, London School of Hygiene and Tropical Medicine, London, UK; Nancy Devlin, PhD Director of Research, UK NHS Office for Health Economics, London, UK; Lewis E. Kazis, ScD, Director, Department of Health Policy and Management, Boston University School of Public Health, Boston, MA, USA

Sandringham Suite

PRO have come of age as sources of information for health care systems policy decisions. In this plenary session, three experts will present insights on programs that have helped shape health care in the US and UK that are based on PRO data. will discuss the routine use of PROMs to compare health service providers in the United States. Richard Lilford PhD, FRCP, FRCOG, FFPHM, Professor of Clinical Epidemiology, Director of Birmingham Clinical Research Academy will moderate a discussion among health policy researchers in the UK and US on the use of PROM for policy decisions, asking "What have we learned and where should we go now?"

Invited speakers include:

- Professor Nick Black, MD, London School of Hygiene and Tropical Medicine who will provide an overview of the UK's National PROMs Programme.
- Professor Nancy Devlin, PhD Director of Research, UK NHS Office for Health Economics who will present "Getting the most out of PROMs: putting health outcomes at the heart of NHS decision-making".
- Professor Lewis E. Kazis, Sc.D, Director, Department of Health Policy and Management, Boston University School of Public Health who will present "The routine use of PROMs to compare health service providers in the United States. What have we learned?"

8:00 am - 6:45 pm

#### Poster Session 2 on display

Viscount Suite and Foyer

Poster numbers 105 through 208 are on display today (see page 43 through 48)

9:30 - 9:45 am

**Break** 

West Wing Lobby

9:45 – 11:15 am

**Concurrent Oral Sessions** 

Instrument Development Chair: Claire Gilbert, MsC Sandringham Suite

#### 1183/Development of the individualised Eye-Dependent Quality of Life Questionnaire: EyeDQoL

Leonie S. Brose, Psychology, Royal Holloway, University of London, Egham, Surrey, UK, Jens Dawczynski, Eye Clinic, Friedrich-Schiller University of Jena, Jena, Germany, Geeta Menon, Eye Clinic, Frimley, Park Hospital NHS Foundation Trust, Frimley,

Surrey, UK, Clare Bradley, Psychology and Health Psychology Research Ltd, Royal Holloway, University of London, Egham, Surrey, UK

#### 1611/The EUROHIS-QOL 8: Comparative measurement properties to its parent WHOQOL-BREF measure

Neusa S. Rocha, Psychiatry, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS, Brazil, Mick J. Power, Psychology, University of Edinburgh, Edinburgh, United Kingdom, Donald Bushnell, Health Research Associates, Seattle, WA, Marcelo P. Fleck, Psychiatry, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS, Brazil

#### 1718/Developing an oral HRQL measure for 5-year-olds

Georgios Tsakos, Epidemiology & Public Health, UCL, London, UK, William Wright, Dental Public Health, University of Glasgow, Glasgow, U.K., Yvonne Blair, National Dental Inspection Programme, NHS Greater Glasgow and Clyde, Glasgow, U.K., Huda Yusuf, Epidemiology & Public Health, UCL, London, U.K., Claire-Louise Hodges, Alex McMahon, Dental Public Health, University of Glasgow, U.K., Richard G. Watt, Epidemiology & Public Health, UCL, London, U.K., Lorna Macpherson, Dental Public Health, University of Glasgow, Glasgow, U.K.

### 1246/Developing and utilizing the EORTC QLQ-SWB36: a spiritual wellbeing measure for palliative care patients with cancer

Bella Vivat, Health Sciences and Social Care, Brunel University, Uxbridge, Middlesex, UK, Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, UK, Juan I. Arraras, Oncology, Hospital de Navarra, Pamplona, Navarra, Spain, Gudlaug H. Åsgeirsdottir, Palliative Care Unit, National University Hospital, Reykjavik, Iceland, Anne Bredart, Psycho-Oncology Unit, Institut Curie, Paris, France, Anna Costantini, Psychooncology Unit, Sant'Andrea Hospital, Sapienza University of Rome, Rome, Italy, Fabio Efficace, Health Outcomes Research Unit, GIMEMA: Italian Group for Adult Hematologic Diseases, Rome, Italy, Kunihiko Kobayashi, Respiratory Medicine, Saitama International Medical Center, Hidaka-city, Japan, Valgerdur Sigurdadottir, Palliative Care Unit, National University Hospital, Reyjkavik, Iceland, Susanne Singer, Medical Psychology and Medical Sociology, University of Leipzig, Leipzig, Germany

#### Assessment Mode Technology

Chair: Fabio Efficace, PhD

Sovereign Suite

### 1136/Just like the film: development of a computer-animation questionnaire to improve the measurement of functional limitations of patients with hip or knee osteoarthritis

Caroline B. Terwee, Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands, Charlotte Coopmans, Health and Life Sciences, Faculty of Earth and Life, Free University Amsterdam, Amsterdam, the Netherlands, Wilfred Peter, Department of Physiotherapy, Leo D. Roorda, Department of Rehabilitation Medicine and Psychology, Jan van Breemen Institute, Amsterdam, the Netherlands, Rudolf W. Poolman, Vanessa Scholtes, Department of Orthopaedic Surgery, Onze Lieve Vrouwe Gasthuis, Amsterdam, the Netherlands, Jaap Harlaar, Rehabilitation Medicine, Henrica C. de Vet, Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, the Netherlands

#### 1423/Do cancer patients feel comfortable with QoL electronic data collection?

Alexandra Oliveira, Foundation for Sciences and Technology, Health Sciences, University of Aveiro, Aveiro, Portugal, Pedro L. Ferreira, Centre for Health Studies, University of Coimbra, Coimbra, Portugal, Francisco L. Pimentel, Health Sciences, University of Aveiro, Aveiro, Portugal

### 1006/Perceived Barriers to Implementing the Patient-Reported Outcomes-Common Toxicity Criteria Adverse Event (PRO-CTCAE) System in Cancer Clinical Trials

Deborah Watkins Bruner, Biobehavioral Health Sciences Division, University of Pennsylvania School of Nursing, Philadelphia, PA, Laura J. Hanisch, Psychiatry, University of Pennsylvania, Philadelphia, PA, Bryce B. Reeve, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, Lori M. Minasian, Division of Cancer Prevention, Julia H. Rowland, Division of Cancer Control and Population Sciences, Ann M. O'Mara, Division of Cancer Prevention, National Cancer Institute, Bethesda, MD, Laura Sit, Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, NY, Jeff A. Sloan, Health Sciences Research, Mayo Clinic, Rochester, MN, Charles S. Cleeland, Symptom Research, The University of Texas M. D. Anderson Cancer Center, Houston, TX, Andrea M. Denicoff, Edward L. Trimble, Division of Cancer Treatment and Diagnosis, Diane St. Germain, Division of Cancer Prevention, Steven B. Clauser, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, Cindy Geoghegan, Patient and Partners LLC, Madison, CT, Diane B. Paul, Patient Advocate, Brooklyn, NY, Amy P. Abernethy, Medicine, Duke University School of Medicine, Durham, NC, Deborah Schrag, Medicine, Dana-Farber Cancer Institute, Boston, MA, Ethan M. Basch, Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, NY

#### 1622/A Randomized Trial of Weekly Symptom Telemonitoring in Advanced Lung Cancer

Susan Yount, Nan Rothrock, Maria Corona, Rebecca Polster, Michael Bass, Jennifer Beaumont, David Cella, Medical Social Sciences, Northwestern University, Chicago, IL

#### Pain

Chair: Lena Ring, PhD

Balmoral Suite

1578/Can Severity and Impact be Combined? An example using pain intensity and interference, in palliative

#### care and chronic pain patients.

Peter M. Fayers, Public Health, University of Aberdeen, Aberdeen, UK, Marianne J. Hjermstad, Oncology, Oslo University Hospital, Oslo, Norway, Pål Klepstad, Anaesthesiology and Acute Medicine, St. Olavs University Hospital, Trondheim, Norway, Jon Håvard Loge, Oncology, Oslo University Hospital, Oslo, Norway, Augusto T. Caraceni, Rehabilitation and Palliative Care Unit, National Cancer Institute, Milan, Italy, Petter Borchgrevink, Anaesthesiology and Acute Medicine, St. Olavs University Hospital, Trondheim, Norway, Stein Kaasa, Cancer Research and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway

#### 1625/Do People Interpret and Respond to Questions About Their Pain in a Comparable Manner?

Richard Sawatzky, Nursing, Trinity Western University, Langley, British Columbia, Canada, Jacek A. Kopec, Eric C. Sayre, Population & Public Health, Pamela A. Ratner, Nursing, Bruno D. Zumbo, ECPS, Measurement, Evaluation & Research Methodology, University of British Columbia, Vancouver, British Columbia, Canada

### 1410/Interactions between cancer type, pain and personality type on self reported Quality of Life (QL) responses

Colin D. Johnson, Gurpreet Ghir, Kate Goyder, Jessica Lightburn, Lidia Machado, Surgery, University of Southampton, Southampton, hants, UK

### 1241/Willingness-to-Pay for a Quality-Adjusted Life-Year Due to Pain Associated with Herpes Zoster: Patient and Community Perspectives

Ismael R. Ortega-Sanchez, Nat Center for Immunization and Respiratory Diseases, Centers for Disease Control and Prevention, Atlanta, GA, Tracy A. Lieu, Department of Ambulatory Care and Prevention, Harvard Pilgrim Health Care, Harvard Medical School, Boston, MA, Tomas Ray, Division of Research, Kaiser Permanente, Oakland, CA, Ken Kleiman, Department of Ambulatory Care and Prevention, Harvard Pilgrim Health Care, Harvard Medical School, Boston, MA, Donna Rusinak, Department of Ambulatory Care and Prevention, Harvard Pilgrim Health Care, Harvard Medical School, Boston, GA, Lisa A. Posser, Department of Population Medicine, Harvard Pilgrim Health Care, Boston, MA

#### Theory

Chair: Ivan Barofsky, PhD Hilton Meeting Rooms 1-6

#### 1691/The PRO Concept Taxonomy: A Structure For Improving Communication About Health Outcomes

Pennifer Erickson, Public Health Sciences, Pennsylvania State Univ., State College, PA, Richard J. Willke, Global Outcomes Research, Pfizer, Inc., Peapack, NJ

#### 1451/Psychosocial Biases in Quality of Life (QOL) Assessments

Carolyn C. Gotay, Population & Public Health, David Osoba, Medicine, University of British Columbia, Vancouver, BC, Canada

#### 1235/Conceptual issues in QoL research

Jacobien M. Kieffer, Gijsbert H. Verrips, Johan Hoogstraten, Social Dentistry and Behavioural Sciences, Academic Centre of Dentistry Amsterdam, Amsterdam, The Netherlands

### 1106/Measurement Properties: A new framework to contribute to the debate between the field of clinimetrics and psychometrics

Maja Stupar, Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada, Dorcas Beaton, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada, Pierre Côté, Eleanor Boyle, J David Cassidy, Toronto Western Research Institute, University Health Network, Toronto, ON, Canada

11:15 – 11:30 am **Break** *West Wing Lobby* 

11:30 am – 1:00 pm Concurrent Oral Sessions

Psychometric Methods Chair: Neil Aaronson, PhD Sandringham Suite

#### 1733/Beyond traditional psychometric methods: Can Rasch help the DASH?

John P. Zajicek, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, Devon, UK, Stefan J. Cano, Louise E. Barrett, Jeremy C. Hobart, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, Devon, United Kingdom

1645/Application of Rasch Analysis to a Novel Dermatology-Specific Quality of Life Measure for Adolescents

#### with Skin Disease

Sam Salek, Sarah-Jane Burton, Pharmacy, Mohammad Basra, Dermatology, Cardiff University, Cardiff, UK

#### 1103/Towards a generalized HRQoL measurement model

Paul Krabbe, Epidemiology, Biostatistics & HTA, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

#### 1406/Developing a health state classification system for dementia using Rasch analysis

Brendan J. Mulhern, School of Health and Related Research, University of Sheffield, Sheffield, UK, Sarah Smith, Health Services Research & Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom, John Brazier, Donna Rowen, School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom, Donna Lamping, Health Services Research & Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom, Martin Knapp, NIHR School for Social Care Research, London School of Economics and Political Science, London, United Kingdom, Vanessa Loftus, Old Age Psychiatry, SLaM Bethlem and Maudsley, Beckenham, Kent, United Kingdom, Sube Banerjee, Centre for Inovation and Evaluation in Mental Health, Institute of Psychiatry, London, United Kingdom

#### **Translation and Cross-Cultural Issues**

Chair: Katrin Conway, MA Hilton Meeting Rooms 1-6

### 1571/International co-validation of a new international quality of life instrument specific to physical appearance: BeautyQoL

Ariel Beresniak, GENEVA, Switzerland, de Linares Yolaine, Research, L'Oréal International, Asnieres sur Seine, France, Pascal Auquier, Public Health, Medecine University, Marseille, France, Gerarld Krueger, Dermatology, University of Utah, Salt Lake City, Sergio Talarico, Dermatology, Federal University of Sao Paulo, Sao Paulo, Brazil, Kiichiro Tsutani, Drug Policy and Management, University of Tokyo, Tokyo, Japan, Barbara Walkiewicz-Cyranska,, Dermatology, Stowarzyszenie Lekarzy Dermatologów Estetycznych, Warszawa, Poland, Genevieve Berger, Medical Imaging, University Pierre & Marie Curie, Paris, France

#### 1158/A Pilot Study on Validation of Traditional Chinese FACT-C on Patients with Colorectal Neoplasm

Carlos King Ho Wong, Cindy Lo Kuen Lam, Family Medicine Unit, Department of Medicine, The University of Hong Kong, Ap Lei Chau, Hong Kong Island, Hong Kong, Wai Lun Law, Jensen Tung Chung Poon, Department of Surgery, The University of Hong Kong, Queen Mary Hospital, Hong Kong, Pierre Chan, Department of Medicine, Hospital Authority, Queen Mary Hospital, Hong Kong

#### 1560/IRT-based Assessement of Differential Item Functioning in HRQL studies

Christophe Lalanne, Martin Duracinsky, Andrew R. Armstrong, Olivier Chassany, Department of Clinical Research and Development, Assistance Publique-Hôpitaux de Paris, Paris, France

#### 1669/Copyright of translations of PRO measures: rules and applications

Caroline Anfray, MAPI Institute, Lyon, France, Katrin Conway, Catherine Acquadro, MAPI Research Trust, Lyon, France, Sonya Eremenco, United BioSource Corporation, Bethesda, MD

#### Oncology II

Chair: Ali Choucair, MD

Balmoral Suite

#### 1474/Influencing Ovarian Cancer Clinical Care through HRQOL Measurement

Lari Wenzel, Medicine and Public Health, University of California, Irvine, Irvine, CA, Vivian E. von Gruenigen, Obstetrics & Gynecology, Summa Health System, Akron, OH, Helen Q. Huang, Gynecologic Oncology Group Statistical and Data Cent, Roswell Park Cancer Institute, Buffalo, NY, Karen M. Gil, Obstetrics & Gynecology, Akron General Medical Center, Akron, OH, Heidi E. Frasure, Reproductive Biology, Case Western Reserve University, Cleveland, OH, Bradley J. Monk, Obstetrics & Gynecology, University of California, Irvine, Orange, CA, Peter G. Rose, Ostetrics & Gynecology, Cleveland Clinic, Cleveland, OH, Deborah K. Armstrong, Obstetrics & Gynecology, Johns hopkins University, Baltimore, MD, David Cella, Medical Social Science, Northwestern University, Chicago, IL

### 1498/Quality of life detriments through lymphoedema of the legs in gynaecological cancer survivors: a prospective assessment

Monika Janda, School of Public Health, Queensland University of Technology, Kelvin Grove, Brisbane, QLD, Australia, Andreas Obermair, Queensland Centre for Gynaecologic Oncology, Royal Brisbane and Women's Hospital, Herston, QLD, Australia, Sandi Hayes, School of Public Health, Queensland University of Technology, Kelvin Grove, Brisbane, QLD, Australia, Hildegard Reul-Hirche, Physiotherapy, Royal Brisbane and Women's Hospital, Herston, QLD, Australia, Leigh Ward, Department of Biochemistry, University Queensland, St Lucia, QLD, Australia

### 1652/Is health related quality of life a prognostic factor of overall survival in metastatic pancreatic denocarcinoma?

Franck Bonnetain, Biostatistics and epidemiology unit, Centre Georges François Leclerc Cancer care Center, Dijon, France, Emilie Maillard, Biostatistics FFCD, Fédération Francophone de Cancérologie Digestive, Dijon, FRANCE, Jean François Seitz,

Gynecology, APHM La Timone, Marseille, FRANCE, Laurent Bedenne, Biostatistics FFCD, Fédération Francophone de Cancérologie Digestive, Dijon, FRANCE, Laetitia Dahan, Gastroenterology, APHM La Timone, Marseille, FRANCE

### 1424/The EORTC QLQ-INFO25 questionnaire: an instrument to assess the information administered to cancer patients. Results of an international validation study

Juan Ignacio Arraras, Medical and Radiotherapeutic Oncology, Hospital de Navarra, Pamplona, Navarra, Spain, Eva Greimel, Department of Obstetrics and Gynaecology, Medical University of Graz, Graz, Austria, Orhan Sezer, Hematology and Oncology, University Hospital Hamburg, Hamburg, Germany, Wei-Chu Chie, Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan, Mia Bergenmar, Department of Oncology, Karolinska Institutet Hospital Dep OncologyPathology, Stockholm, Sweden, Anna Constantini, Psychooncology Unit, Sant'Andrea Hospital, Sapienza University of Rome, Rome, Italy, Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, U.K., Karin Kuljanic Vlasic, Gynaecology and Obstetrics, Clinical Hospital Center Rijeka, Rijeka, Croatia, Galina Velikova, University of Leeds, St James's Institute of Oncology, Leeds, U.K.

Obesity

Chair: Donald Patrick, PhD

Sovereign Suite

#### 1556/Predictors of HRQOL in children and adolescents

Kristin Haraldstad, Sølvi Helseth, Dep. of Nursing Research, Oslo University College, N-0167 Oslo, Norway, Knut andreas Christophersen, Institute of Political Science, University of Oslo, 0317 -Oslo, Norway, Hilde Eide, Dep of Nursing research, Oslo University College, Oslo, Norway, Gerd karin Natvig, Department of Public Health and Primary Care, University of Bergen, Bergen, Norway

#### 1190/Weight and Quality of Life of Youth in Mexico and the United States: A Comparative Study

Leo S. Morales, Group Health Research Institute, Seattle, WA, Yvonne Flores, Unidad de Investigación Epidemiológica y en Servicio, Instituto Mexicano del Seguro Social, Cuernavaca, Morelos, Mexico, Andrea Hobby, Health Services/GIM, UCLA, Los Angeles, CA, Todd C. Edwards, Health Services, Univ of Washington, Seattle, WA, Donald L. Patrick, Health Services, University of Washington, Seattle, Washington, Jorge Salmerón, Unidad de Investigación Epidemiológica y en Servicio, Instituto Mexicano del Seguro Social, Cuernavaca, Morelos, Mexico, Anne M. Skalicky, Health Services, University of Washington, Seattle, WA

#### 1740/HRQL evolution in overweight adolescents improving their BMI

Emilie Bonsergent, EA4360 APEMAC laboratory, School of Public Health, Vandoeuvre-lès-Nancy, France, Nelly Agrinier, Epidemiology and clinical evaluation department, Nancy University Hospital, Vandoeuvre-lès-Nancy, France, Joseph Benie-Bi, Sabrina Tessier, Serge Briançon, EA4360 APEMAC laboratory, School of Public Health, Vandoeuvre-lès-Nancy, France

### 1608/Between psychological characteristics and health-related quality of life (HRQOL) of adolescent females with a tendency for eating disorders

Yuko Sasaki, Takako Utumi, Masumi Abe, Maya Sato, Emi Suzuki, Sanae Adachi, Health and Nutrition, Sendai Shirayuri Women's College, Sendai, Miyagi, Japan, Yoko Goto, Occupational Therapy, School of Health Science, Sapporo Medical University, Sapporo, Japan

1:00 - 2:00 pm

Lunch on Your Own | SIG Meetings | Committee Meetings

Kids SIG Response Shift SIG 2011 Program Committee Chapter Chairs Committee York Room Lancaster Room Hilton Meeting Room 7-10 4th Floor Presentation Room

2:00 – 3:30 pm

**Concurrent Symposia** 

Invited Symposium: CURRENT METHODS FOR MEASURING AND VALUING HEALTH STATES: METHOD-OLOGICAL ISSUES AND POLICY IMPLICATIONS

Chair: William Lenderking, PhD

Sandringham Suite

Symposium 1538: THE CHALLENGES OF SYMPTOM ASSESSMENT IN CLINICAL RESEARCH: ILLUSTRATIONS IN GASTROINTESTINAL CONDITIONS

Chair: Tara Symonds, PhD

Sovereign Suite

**Individual Abstract 1597** 

### DEVELOPMENT OF SYMPTOM MEASURES REFLECTING THE RELATIVE IMPACT OF SYMPTOMS ON HEALTH-RELATED QUALITY OF LIFE: APPLICATION TO CHRONIC CONSTIPATION

Antoine Regnault, Gaye Siliman, Statistics & psychometrics, Mapi Values, René Kerstens, Biometrics and Data Management, Movetis, Dominique Dubois, Outcome Research, Patient Value Solution, Claire Marant, Patient-Reported Outcomes, Mapi Values

#### **Individual Abstract 1600**

#### THE SYMPTOMS OF IRRITABLE BOWEL SYNDROME WITH CONSTIPATION (IBS-C): RESULTS OF QUALITATIVE INTER-VIEWS WITH CHILDREN AND THEIR PARENTS

Robyn T. Carson, Health Economics & Outcomes Research, Forest Research Institute, Jersey City, NJ, Rob Arbuckle, Linda Abetz, Patient-Reported Outcomes, Mapi Values, Barbara E. Lewis, Health Economics and Outcomes Research, Ironwood Pharmaceuticals, Laura-Jayne Hunter, Patient-Reported Outcomes, Mapi Values, Jeffrey Johnston, \*, Ironwood Pharmaceuticals, Steven J. Shiff, Clinical Development, Forest Research Institute

#### **Individual Abstract 1603**

### SIMILARITIES AND DIFFERENCES IN THE EXPRESSION OF SYMPTOMS ACROSS COUNTRIES: THE TRANSLATIONS OF THE PAGI-SYM 20

Isabelle Mear, Mapi Institute, Lyon, France, Katrin Conway, Mapi Research Trust, Antoine Regnault, Psychometrics & Statistics, Mapi Values, Catherine Acquadro, Mapi Research Trust

#### **Individual Abstract 1619**

#### MAKING SENSE OF SYMPTOM DATA FROM CLINICAL TRIALS - THE REGULATORY CHALLENGE

Olivier Chassany, Université Paris 7 Denis-Diderot, Assistance Publique - Hopitaux de Paris, Paris, France

### Symposium 1163: TRANSLATING PATIENT-REPORTED OUTCOMES INTO DECISION MAKING IN ONCOLOGY

Chair: Sam Salek, PhD

Balmoral Suite

#### **Individual Abstract 1201**

#### FACTORS INFLUENCING QUALITY OF LIFE IN HODGKIN'S DISEASE

Henning H. Flechtner, Klinik for Psychiatrie, Psychotherapie, Otto-von-Guericke-Universitet, Magdeburg, Germany

#### **Individual Abstract 1204**

### ENHANCING PATIENT-PHYSICIAN COMMUNICATION BY ASSESSING CANCER-RELATED SYMPTOMS: DISCREPANCIES IN ESTIMATION OF SYMPTOM SEVERITY BETWEEN A PATIENT AND A PHYSICIAN

Tatyana I. Ionova, Quality of Life Dept., Multinational Center for Quality of Life Research, St.Petersburg, Russia, Svetlana A. Kalyadina, Quality of Life Dept., Multinational Center for Quality of Life Research, Andrei A. Novik, Hematology Dept., National Medical Surgical Center

#### Individual Abstract 1527

#### PRO IN DECISION MAKING PARADIGM IN CLINICAL ONCOLOGY: APPLICATION TO CLINICAL PRACTICE

Andrei A. Novik, Hematology Dept., National Medical Surgical Center, Moscow, Russia, Tatyana I. Ionova, Quality of Life Dept., Multinational Center for Quality of Life Research, Gary Gorodokin, Quality of Life Dept., New Jersey Center for Quality of Life and Health Out

#### Symposium 1458: USING THE WHOQOL - A CONTEMPORARY VIEW

Chair: Suzanne M. Skevington, PhD

Hilton Meeting Rooms 1-6

#### **Individual Abstract 1090**

### COMPARING THE IMPORTANCE OF DIFFERENT ASPECTS OF QUALITY OF LIFE TO OLDER ADULTS ACROSS DIVERSE CULTURES

Anita E. Molzahn, Nursing, University of Alberta, Edmonton, Alberta, Canada, Mary Kalfoss, Nursing, Diakanova University College, Oslo, Norway, Kara Schick Makaroff, Nursing, University of Victoria, Victoria, British Columbia, Canada, Suzanne M. Skevington, Psychology, University of Bath, Bath, UK

#### **Individual Abstract 1285**

### CREATING A SHORT-FORM OF THE WHOQOL-SRPB: ASSESSING QUALITY OF LIFE IN SPIRITUAL, RELIGIOUS AND PERSONAL BELIEFS

Keely S. Gunson, Suzanne M. Skevington, Kathyrn A. O'Connell, Psychology, WHO centre for the study of QOL, University of Bath, Bath, Somerset, England

#### Individual Abstract 1473

DEVELOPING THE WHOQOL-OLDSF (SHORT FORM)

Graeme Hawthorne, Psychiatry, The University of Melbourne, Alain LePlege, Département d'Histoire et de Philosophie des Science, University of Paris

#### Individual Abstract 1039

THE WHOQOL-PAIN: DERIVATION OF AN INSTRUMENT TO ASSESS QUALITY OF LIFE IN PEOPLE WITH CHRONIC PAIN

Victoria L. Mason, Psychological Sciences, University of Worcester, Worcester, UK, Suzanne M. Skevington, Department of Psychology, University of Bath, Bath, UK

3:30 – 3:45 pm **Break** *West Wing Lobby* 

3:45 – 5:15 pm

**Concurrent Oral Sessions** 

Responsiveness II

Chair: Josephine Norquist, MSc

Sandringham Suite

### 1772/Clinically Significant Effect Sizes for Survival and Response Endpoints using the $\frac{1}{2}$ Standard Deviation Rule

Jeff Sloan, Paul Novotny, Daniel J. Sargent, Paul Decker, Rui Qin, Health Sciences Research, Mayo Clinic, Rochester, MN

#### 1507/Relative responsiveness and statistical efficiency of QLQ-C30 v FACT-G

Madeleine King, Melanie Bell, Daniel Costa, Phyllis Butow, Psycho-Oncology Cooperative Research Group (PoCoG), University of Sydney, Sydney, NSW, Australia, Byeongsang Oh, Medicine, Concord Repatriation General Hospital, Sydney, NSW, Australia

### 1148/Agreement About Identifying Patients Who Change Over Time: Cautionary Results in Cataract and Heart Failure Patients

David Feeny, Center for Health Research, Kaiser Permanente, Portland, OR, Karen Spritzer, Ron D. Hays, Honghu Liu, Medicine, UCLA, Los Angeles, CA, Theodore Ganiats, Family and Preventive Medicine, UC San Diego, La Jolla, CA, Robert M. Kaplan, Health Services, UCLA, Los Angeles, CA, Mari Palta, Population Health Sciences, University of Wisconsin, Madison, WI, Dennis Fryback, Population Health Sciences, University of Wisconsin, Huntington Beach, CA

#### 1725/Effect sizes can be misleading: Is it time to change the way we measure change?

Jeremy C. Hobart, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, Devon, UK, Stefan J. Cano, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, Devon, United Kingdom

Economic Evaluation II Chair: Paul Kind, PhD Sovereign Suite

#### 1186/Relationships Between EQ-5D and FACT Scores in Patients with Esophageal or Gastric Cancer

David K. Ingledew, Psychology, Bangor University, Bangor, Gwynedd, UK, Rhiannon Whitaker, N Wales Organisation for Randomised Trials in Health, Bangor University, Bangor, Gwynedd, United Kingdom, Ian T. Russell, Medicine, Swansea University, Swansea, Glamorgan, United Kingdom, Daphne Russell, N Wales Organisation for Randomised Trials in Health, Bangor University, Bangor, Gwynedd, United Kingdom

### 1069/Assessing Health-related Quality of Life (HRQL) in Lung Transplant Recipients using the Health Utility Index Mark 3 (HUI3)

Maria Jose Santana, Lung transplant program, University of Alberta, Edmonton, AB, Canada, David Feeny, Center for Health Research, Kaiser Permanente Northwest, Portland, Oregon, Sunita Ghosh, Experimental Oncology, Cross Cancer Institute, Edmonton, Alberta, Canada, Roland G. Nador, Justin Weinkauf, Kathleen Jackson, Dale C. Lien, Lung transplant program, University of Aberta Hospital, Edmonton, AB, Canada

#### 1737/Health gain for a controversial operation on appropriately selected cases: VTs in childhood OME

Mark P. Haggard, Helen Spencer, Experimental Psychology, University of Cambridge, Cambridge, UK, Sarah C. Smith, Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, UK

#### 1568/Using QALYs to assess changes in the impact of chronic conditions on population HRQL

Oriol Cunillera, Health Services Research Unit, IMIM-Institut de Recerca Hospital del Mar, Barcelona, Spain, Spain, Michael Herdman, Health Services Research Unit, CIBERESP, IMIM-Institut de Recerca Hospital del Mar, Barcelona, Spain, Spain, Ridard Tresserras, Direcció General de Planificació i Avaluació, Departament de Salut de la Generalitat de Catalunya, Barcelona, Spain, Spain, Luis Rajmil, Barcelona, Spain, Spain, Gemma Vilagut, Health Services Research Unit, CIBERESP, IMIM-Institut de Recerca

Hospital del Mar, Barcelona, Spain, Spain, Pilar Brugulat, Anna Mompart, Antonia Medina, Direcció General de Planificació i Avaluació, Departament de Salut de la Generalitat de Catalunya, Barcelona, Spain, Spain, Yolanda Pardo, Health Services Research Unit, IMIM-Institut de Recerca Hospital del Mar, Barcelona, Spain, Spain, Jordi Alonso, Health Services Research Unit, CIBERESP, IMIM-Institut Recerca Hospital del Mar, UPF, Barcelona, Spain, Spain, Montse Ferrer, Health Services Research Unit, CIBERESP, IMIM-Institut Recerca Hospital del Mar, UAB, Barcelona, Spain, Spain

Clinical Decision Making Chair: Galina Velikova, MD, PhD Balmoral Suite

### 1236/Velikova's Content Analysis System (VCAS): Inter-rater reliability and Feasibility regarding characterization of aspects related to HRQoL and medical decision making

Hanna Fagerlind, Ida Bergström, Åsa Kettis Lindblad, Department of Pharmacy, Uppsala University, Uppsala, Sweden, Galina Velikova, Cancer Research UK centre, St James's Institute of Oncology St James's Hospital, Leeds, United Kingdom, Bengt Glimelius, Oncology, Radiology and Clinical Immunology, Lena Ring, Department of pharmacy, Uppsala University, Uppsala, Sweden

### 1176/The PANORAMA Pan-European Survey of Type 2 Diabetes - Patient vs Doctor Ratings of Patients' Treatment Satisfaction

Clare Bradley, Psychology, Royal Holloway, University of London, Egham, Surrey, UK, Eveline Eschwège, Epidemiology and Public Health UMR-S 1018, INSERM, Faculty of Medicine Paris IX, Villejuif, France, Pedro de Pablos-Velasco, Endocrinology, Dr Negrin Hospital, Las Palmas University, Las Palmas de Gran Canaria, Spain, Klaus Parhofer, Medizinische Klinik II - Grosshadern, University Clinic, Munich, Germany, Dominique Simon, Service de Diabétologie, Hôpital de la Pitié, CESP - INSERM U-1018, Paris, France, Linda Gönder-Frederick, Psychiatry and Neurobehavioral Sciences, University of Virginia Health System, Charlottesville, VA

### 1638/Development of a banding system for the Renal Quality of Life Profile (RQLP): An aid to clinical decision making

Nadine Aawar, Pharmacy, Cardiff University, Cardiff, UK, Sam Salek, Pharmacy, Cardiff University, Cardiff, United Kingdom, Richard Moore, Steve Riley, Renal, University Hospital of Wales, Cardiff University, Cardiff, United Kingdom

1724/Health-related quality of life is an independent determinant of adherence to drugs in HIV-infected people Rita Murri, Antonella Cingolani, Infectious Diseases, Catholic University of Rome, Rome, Italy, Andrea De Luca, Infectious Diseases, Catholic University of Rome and University of Siena, Rome, Italy, Simona Di Giambenedetto, Giuseppe Marasca, Giuseppe De Matteis, Ilaria Mastrorosa, Carmela Pinnetti, Massimo Fantoni, Enrica Tamburrini, Infectious Diseases, Catholic University of Rome, Rome, Italy

Breast Cancer - Oncology III Chair: Carolyn Gotay, PhD Hilton Meeting Rooms 1-6

1110/The Relationship between Distress and Quality of Life in Women Recently Diagnosed with Breast Cancer Barbara A. Head, Internal Medicine, University of Louisville School of Medicine, Louisville, KY

1701/Longitudinal Joint Pain in Postmenopausal Women with Early Breast Cancer Taking Aromatase Inhibitors Liana D. Castel, General Internal Medicine and Public Health, Katherine Hartmann, Obstetrics/Gynecology, Stephen Deppen, Thoracic Surgery, Vanderbilt University Medical Center, Nashville, TN, Ingrid Mayer, David Johnson, Hematology/Oncology, Vanderbilt-Ingram Cancer Center, Nashville, TN, Chad Boomershine, Rheumatology and Immunology, Vanderbilt University Medical Center, Nashville, TN, Vandana G. Abramson, Hematology/Oncology, Anuradha (Bapsi) Chakravarthy, Radiation Oncology, Vanderbilt-Ingram Cancer Center, Nashville, TN, Sarah Elizabeth McLellan, Institute of Medicine and Public Health, Vanderbilt University Medical Center, Nashville, TN, Debra L. Friedman, Hematology/Oncology, Vanderbilt-Ingram Cancer Center, Nashville, TN, David Cella, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL

### 1757/Measuring and managing patient expectation for breast reconstruction: A new preoperative patient assessment tool

Laura J. Snell, Surgery, Memorial Sloan-Kettering Cancer Center, New York, NY, Stefan J. Cano, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, UK, Anne F. Klassen, Pediatrics, McMaster University, Hamilton, ON, Canada, Colleen M. McCarthy, Amie M. Scott, Peter G. Cordeiro, Andrea L. Pusic, Surgery, Memorial Sloan-Kettering Cancer Center, New York, NY

### 1295/Impact of response shift (RS) in longitudinal post-operative quality of life (QoL) analysis among breast cancer (BC) patients: A randomized multicenter cohort study.

Franck Bonnetain, Biostatistics and epidemiology unit, Centre Georges François Leclerc Cancer care Center, Dijon, France, Thierry Conroy, Oncology, Centre Alexis Vautrin, Vandoeuvre-lès-Nancy, France, Michel Velten, Epidemiology, Centre Paul Strauss, Strasbourg, France, Damien Jolly, Epidemiology, CHRU Reims, Reims, France, Mariette Mercier, Biostatistics, CHRU Besançon, Besançon, France, Sandrine Dabakuyo, Biostatistics and epidemiology unit, Sylvain Causeret, Jean Cuisenier, Surgery, Centre Georges François Leclerc Cancer care Center, Dijon, France, Olivier Graesslin, Gynecology, CHRU Reims, Reims, France, Melanie Gauthier, Biostatistics and epidemiology unit, Centre Georges François Leclerc Cancer care Center, Dijon,

FraqnceE, Françis Guillemin, Centre d'épidémiologie clinique, CHRU Nancy, Vandoeuvre-Les-Nancy, France

5:15 – 6:45 pm

Reception and Meet the Author Poster Session

Viscount Suite and Foyer

6:45 pm

SIG Meeting | Committee Meeting

6:45 – 7:45 pm

Strategic Partnership Committee

Hilton Meeting Rooms 1-6

6:45 – 8:15 pm

**New Investigator SIG** 

Balmoral Suite

#### Saturday, October 30, 2010

7:00 am - 4:00 pm

#### Registration and Exhibits

West Wing Lobby

A continental breakfast will be served at 7:30 am. Please be sure to visit the exhibits!

7:45 - 9:15 am

**Concurrent Symposia** 

Invited Symposium: INFORMATION SYSTEMS (IS) FOR COLLECTION AND USE OF PRO DATA IN CLINI-CAL PRACTICE

Chair: Carolyn Gotay, PhD

Sandringham Suite

Sharon Kletcho, Claire Synder, Dale Vidal

#### Symposium 1370: DEVELOPMENT AND HEALTH IN CHILDHOOD: SETTING THE STAGE FOR PRO ASSESS-MENT ACROSS THE LIFE COURSE

Chair: Christopher B. Forrest, PhD

Hilton Meeting Rooms 1-6

#### Individual Abstract 1665

### DEVELOPMENT OF CHILDREN'S COGNITIVE CAPABILITIES: IMPLICATIONS FOR PEDIATRIC SELF-REPORT MEASURES Katherine B. Bevans, Pediatrics, Children's Hospital of Philadelphia, PA, USA

#### **Individual Abstract 1679**

#### EMPIRICAL APPROACHES FOR LINKING CHILD AND ADULT PROS

Stephen M. Haley, Health and Disability Research Institute, Boston University School of Public Health, David L. Tulsky, Kessler Foundation Research Center

#### Individual Abstract 1684

### AGE-RELATED CHANGES IN SELF-REPORTED QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS: A MULTILEVEL ANALYSIS ACROSS 13 EUROPEAN COUNTRIES

Ulrike Ravens-Sieberer, Michael Erhart, Center for Obstetrics and Pediatrics, University Medical Center Hamburg-Eppendorf, Luis Rajmil, Catalan Agency for Health Technology Assessment and, Carole Tucker, Physical Therapy, Temple University

#### Individual Abstract 1687

### A LIFE COURSE APPROACH TO PATIENT REPORTED OUTCOMES (PRO) INSTRUMENT DEVELOPMENT: TURNING CHALLENGES INTO OPPORTUNITIES

Donald L. Patrick, Seattle Quality of Life Group, University of Washington

### Symposium 1408: OVERVIEW OF EXISTING AND NOVEL METHODOLOGIES FOR TESTING THE EFFECTIVENESS OF USING PATIENT REPORTED OUTCOMES IN CLINICAL PRACTICE

Chair: David Feeny, PhD

Balmoral Suite

#### **Individual Abstract 1417**

### ASSESSING THE IMPACT OF ROUTINELY MEASURING PATIENT-REPORTED OUTCOMES IN CLINICAL PRACTICE: CRITICAL APPRAISAL OF 34 RANDOMIZED CLINICAL TRIALS

Jose M. Valderas, Division of Public Health and Primary Health Care, NIHR School of Primary Care Research, University of, Mireia Espallargues, Anna Kotzeva, Jordi Alonso, Health Services Research Unit, Institut Municipal d'Investigació Mèdica (IMIM-hospi

#### Individual Abstract 1420

#### ALTERNATIVE DESIGNS AND STATISTICAL CONSIDERATIONS

Peter Fayers, Medical Statistics, Department of Public Health, University of Aberdeen

#### **Individual Abstract 1421**

# APPLYING THE HEALTH TECHNOLOGY ASSESSMENT FRAMEWORK FOR DIAGNOSTIC TECHNOLOGIES TO EVALUATE THE INCLUSION OF PATIENT REPORTED OUTCOMES (PROS) IN ROUTINE CLINICAL CARE OF CHRONICALLY ILL PATIENTS

Maria J. Santana, Division of Pulmunology, Lung Transplant Program, University of Alberta, David Feeny, Center for Health Research, Kaiser Permanente Northwest

#### Saturday

Symposium 1685: ADAPTING PROMS FOR USE WITH DIVERSE POPULATIONS: EXPERIENCES WITH AMERI-

CAN SIGN LANGUAGE
Chair: Steven Barnett, MD

Sovereign Suite

**Individual Abstract 1748** 

DEAF CONSUMERS' HEALTHCARE EXPERIENCES: THE NEED FOR ACCESSIBLE PROM

Steven Barnett, Family Medicine, University of Rochester, Rochester, NY

Individual Abstract 1751

SIGN LANGUAGE HEALTH SURVEYS: DESIGNING & EVALUATING A COMPUTER-BASED INTERFACE

Erika Sutter, Community and Preventive Medicine, University of Rochester, Rochester, NY

**Individual Abstract 1752** 

SIGN LANGUAGE HEALTH MEASURES: TRANSLATION & ADAPTATION

Poorna Kushalnagar, Community and Preventive Medicine, University of Rochester, Rochester, NY

8:00 am - 3:30 pm

Poster Session 3 on display

Viscount Suite and Foyer

Poster numbers 209 through 312 are on display today (see page 48 through 53)

9:15 - 9:30 am

**Break** 

West Wing Lobby

9:30 - 9:45 am

President's Award

Chair: Diane Fairclough, DrPH Speaker: David Feeny, PhD

Sandringham Suite

9:45 – 11:15 am

**Plenary Session** 

Dissemination and Integration of PRO Data into Clinical Care

Chair: ?? Speakers:

Snadringham Suite

"How can the quality of life research community best support clinicians and patients who seek meaningful PRO data for shared medical decision-making and patient advocacy?" is the question that will be considered in the final plenary of the meeting. Each year masses of data are reported about treatments, but often the information is difficult for clinicians and patients to understand and use for decision-making. The session will consider challenges to improving understanding of information needs of patients and clinicians and how these needs might be better met. A patient advocate, a clinician, and a clinician-QOL researcher will consider how to help clinicians and patients can gain more from PRO data for treatment planning. Andrea Pusic will serve as moderator for the panel discussion. Invited speakers include

- Professor Dale Vidal (Director, Center for Informed Choice at Dartmouth Medical Center) who will discuss shared medical decision-making and evidence-based practice.
- Dr. Michael Brundage (radiation oncologist and PRO researcher) who will share his projects for improving clinician and patient understanding of QOL outcomes from clinical trials.
- Mr. Richard Stephens, (patient advocate and patient representative to the Macmillian Cancer Support clinical advisory board)
  who will provide the patient perspective drawn from his own experience as a cancer and heart patient and that of other
  patients regarding information available to patients and what information patients need and want about their treatments.

11:15 – 11:30 am

**Break** 

West Wing Lobby

#### Saturday

11:30 am - 1:00 pm

**Plenary Session:** 

Incorporating PRO in Health Policy Decisions: Where Should We Be Heading

Chair: ?? Panelists:

Sandringham Suite

Representatives from governmental agencies in the US, UK, and EU will discuss the role of PRO in health policy decision-making, what is the current situation and how ISOQOL can help ensure access to, delivery of, and information about effective, affordable healthcare that addresses the clinical needs of patients, their caregivers, and health care providers.

Panelists include:

1:00 – 2:30 pm

**Reception and Meet the Author Poster Session** 

Viscount Suite and Foyer

2:30 - 3:30 pm

ISOQOL Members Meeting

Sovereign Suite

Please see page 8 for a description of this session.

3:30 - 5:15 pm

Meet the Experts: Modern Test Theory and the Future of Health Measurement

Chair: ?? Panelists: Sovereign Suite

Special question and answer session in which world leading measurement experts from the US, UK, and Australia will address questions about the use of Modern Test Theory methods (including Rasch measurement and Item Response Theory) in PRO development and testing, and their use in the future of health assessment research.

Panelists include:

7:00 pm **Conference Banquet** *Viscount Suite* 

#### Poster Session 1 - Thursday

Poster Session 1 Thursday, October 28 Viscount Suite and Foyer

Poster numbers 1 through 104

#### General

### 1/1594/Poor health-related quality of life of mothers after severe preeclampsia: results from a prospective cohort study

Hein Raat, Public Health, Erasmus MC - University Medical Center Rotterdam, Rotterdam, ZH, The Netherlands, Durk Berks, Obstetrics, Ineke Vogel, Meeke Hoedjes, Public Health, Arie Franx, Johannes J. Duvekot, Obstetrics, J. Dik F. Habbema, Public Health, Eric A. P. Steegers, Obstetrics, Erasmus MC, Rotterdam, ZH, Netherlands

#### 2/1387/Choice of Recall Period for PRO Measures: One Size Does Not Fit All

Josephine M. Norquist, Cynthia Girman, Epidemiology, Merck Sharp & Dohme, Corp., North Wales, PA, Sheri Fehnel, Carla DeMuro-Mercon, RTI Health Solutions, Research Triangle Park, NC, Nancy Santanello, Epidemiology, Merck Sharp & Dohme, Corp., North Wales, PA

#### 3/1347/A Targeted Review of Measures of Social Isolation and Perceived Social Support

Jan Sansoni, Nick Marosszeky, Glenn Fleming, Centre for Health Service Development, University of Wollongong, Wollongong, NSW, Australia

#### 4/1085/Psychosocial Consequences of Genetic Testing in Li-Fraumeni Syndrome

Chantal Lammens, Psychosocial Research & Epidemiology, Senno Verhoef, Family Cancer Clinic, Neil Aaronson, Eveline Bleiker, Psychosocial Research & Epidemiology, Netherlands Cancer Institute-Antoni Van Leeuwenhoek, Amsterdam, Netherlands

#### 5/1008/High-risk Pregnancies and Quality of Life

Eva Mautner, Gerda Trutnovsky, Fedor Daghofer, Obstetrics and Gyneacology, Josef W. Egger, Medical Psychology and Therapy, Uwe Lang, Eva Greimel, Obstetrics and Gyneacology, Medical University Graz, Graz, Austria

### 6/1686/Quality of life, Sense of Coherence, Religious and Spiritual aspects in a sample of Iranian family caregivers of patients with breast cancer at the time of diagnosis and six months later.

Sedigheh Khanjari, Neurobiology, Care Sciences and Society, Karolinska Institutet, STOCKHOLM, Sweden, Ann Langius-Eklöf, Örebro Universitet, Örebro, Sweden, Fatemeh Oskouei, Community Health, Iran University of Medical Sciences, Tehran, Iran

### 7/1558/Exploring the contribution of spirituality, religious and personal belief(SRPB) to quality of life(QOL) in Hong Kong Chinese

Kitty Chan, Nursing, The Hong Kong Polytechnic University, Hong Kong SAR, China, Suzanne Skevington, Psychology, University of Bath, University of Bath, Bath, UK

### 8/1361/Development and validation of an observational instrument for the measurement of canine HRQL in veterinary medicine, using dog owner as respondent

Lesley Wiseman-Orr, Statistics, University of Glasgow, Glasgow, UK, Jacky Reid, Small Animal Clinical Studies, University of Glasgow, Kippen, Stirlingshire, UK, Marian Scott, Statistics, Andrea Nolan, Division of Cell Sciences, University of Glasgow, Glasgow, UK

### 9/1765/Cross-Cultural Adaptation and Validation of the Daily Spiritual Experience Scale for the Brazilian culture

Acacia L. Oliveira, Miako Kimura, Lina S. Mishima, Medical Surgical Nursing, University of Sao Paulo, Sao Paulo, Sao Paulo, Brazil

#### 10/1089/Spirituality, Depression, Symptoms of Distress and Other QOL

Arun Kandasamy, SANTOSH K. CHATURVEDI, GEETHA DESAI, PSYCHIATRY, NATIONAL INSTITUTE OF MENTAL HEALTH AND NEUROSCIENCE, BANGALORE, KARNATAKA, INDIA

#### Clinical Practice & Research

# 11/1349/Influence of vision and quality of life on the medication adherence in elderly with diabetic retinopathy Fernanda F. Jannuzzi, Fernanda A. Cintra, Maria Cecília B. Gallani, Nursing, State University of Campinas, Campinas, São Paulo, Brazil

### 12/1344/The relationship between medication adherence and quality of life among the elderly with diabetic retinopathy

Fernanda F. Jannuzzi, Fernanda A. Cintra, Maria Cecília B. Gallani, Nursing, State University of Campinas, Campinas, São Paulo, Brazil

#### 13/1247/Development of the Eye Treatment Satisfaction Questionnaire: EyeTSQ

Leonie S. Brose, Psychology, Royal Holloway, University of London, Egham, Surrey, UK, Geeta Menon, Eye Clinic, Frimley Park Hospital NHS Foundation Trust, Frimley, Surrey, UK, Jens Dawczynski, Eye Clinic, Friedrich-Schiller University of Jena, Germany, Clare Bradley, Psychology and Health Psychology Research Ltd, Royal Holloway, University of London, Egham, Surrey, UK

#### Poster Session 1 - Thursday

### 14/1316/Assessment of Unidimensionality for the Visual Function Questionnaire-Utility Index (VFQ-UI) Items in Patients with Central Vision Loss

Dennis A. Revicki, Anne M. Rentz, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD, Jonathan W. Kowalski, Global Health Outcomes Strategy & Research, Allergan, Inc., Irvine, CA, Wen-Hung Chen, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD

### 15/1565/Development of pre-validation methodology in the design of a theory-informed instrument: the Aberdeen Glaucoma Questionnaire

Maria Prior, Jennifer M. Burr, Francis Jillian, Jemaima Che Hamzah, Craig R. Ramsay, Augusto Azuara-Blanco, Susan E. Campbell, on behalf of the Glaucoma screening Platform Study, Health Services Research Unit, University of Aberdeen, Aberdeen, Aberdeenshire, UK

### 16/1439/Development of the Patient-Reported Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Ethan Basch, Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, New York, Bryce Reeve, Outcomes Research, National Cancer Institute, Bethesda, MD, Charles S. Cleeland, Symptom Research, The University of Texas M.D. Anderson Cancer Center, Houston, Texas, Jeff A. Sloan, Biomedical Statistics and Informatics, Mayo Clinic, Rochester, Minnesota, Deborah Schrag, Medicine, Dana-Farber Cancer Institute, Boston, Massachusetts, Thomas M. Atkinson, Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, New York, Tito R. Mendoza, Symptom Research, The University of Texas M.D. Anderson Cancer Center, Houston, Texas, Jennifer L. Hay, Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, Amy P. Abernethy, Medicine, Duke University School of Medicine, Durham, North Carolina, Lori Minasian, Cancer Prevention, National Cancer Institute, Rockville, Maryland, Virginia Kwitkowski, Drug Oncology Products, United States Food and Drug Administration, Silver Spring, MD, Ann Marie Trentacosti, Laurie Burke, Study Endpoints and Labeling Development, United States Food and Drug Administration, Silver Spring, Maryland, Laura Sit, Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, New York, Deborah W. Bruner, School of Nursing, University of Pennsylvania, Philadelphia, Pennsylvania

### 17/1683/Development of a Quality of Life Measure for Evaluating Mucopolysaccharidoses: Preliminary Results From Focal Groups

Neusa S. Rocha, Liciane Costa, Psychiatry, Julia Protas, Medical Sciences, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS, Brazil, Fabricio Marchiori, Psychology, Pontificia Universidade Católica do RS, Porto Alegre, RS, Brazil, Heber Maia, Universidade Federal Fluminense, Pediatry, Rio de Janeiro, RS, Brazil, Marcia Ribeiro, Genetics, Universidade Federal do Rio de Janeiro, RJ, Brazil, Angelina Acosta, Universidade Federal do Bahia, Pediatry, Salvador, BA, Brazil, Ida Schwartz, Genetics, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS, Brazil

### 18/1217/Assessing the Clinical Significance of Real-time QOL Data in Cancer Patients Treated with Radiation Therapy(RT)

Michele Y. Halyard, Radiation Oncology, Mayo Clinic, Scottsdale, Az, Jeff A. Sloan, Angelina D. Tan, Pamela J. Atherton, Health Sciences Research, Mayo Clinic, Rochester, Mn, Matthew D. Callister, WIlliam W. Wong, Sujay A. Vora, Steven E. Schild, Jonathon B. Ashman, Radiation Oncology, Amylou C. Dueck, Biostatistics, Denise E. Ciafone, Pamela A. Zimmerman, Patricia A. Burris, Radiation Oncology, Mayo Clinic, Scottsdale, Az

#### 19/1393/Using Group-Based Trajectory Modeling to Examine Heterogeneity of Cancer-Related Symptoms

Qiuling Shi, Symptom Research, David I. Rosenthal, Radiation Oncology, The University of Texas M. D. Anderson Cancer Center, Houston, TX, Tito Mendoza, Symptom Research, The University of Texas, Houston, TX, Charles S. Cleeland, Symptom Research, The University of Texas M. D. Anderson Cancer Center, Houston, TX

### 20/1264/Nursing perceptions in Implementation of Health Related Quality of Life Assessment Oncology daily practice

Maria Teresa D. Sequeira, Health Sciences, Augusta P. Silveira, Health Sciences, Fernando Pessoa University, Porto, Portugal, Lurdes Carvalho, Oncology, Portuguese Oncology Institute, Porto, Portugal, Eurico Monteiro, Health Sciences, Fernando Pessoa University, Porto, Portugal

#### 21/1644/The FACT-G is Valid for Monitoring HRQoL in Non-Hodgkin Lymphoma Patients

Kathleen J. Yost, David T. Eton, Health Sciences Research, Shawna L. Ehlers, Pamela S. Sinicrope, Psychiatry and Psychology, Carrie A. Thompson, Hematology, Mayo Clinic, Rochester, MN, Lori J. Rosenstein, Hematology/Oncology, University of Iowa Hospitals and Clinics, Iowa City, IA, Cristine Allmer, Matthew J. Maurer, Susan L. Slager, Health Sciences Research, Mayo Clinic, Rochester, MN, Brian K. Link, Hematology/Oncology, University of Iowa Hospitals and Clinics, Iowa City, IA, James R. Cerhan, Health Sciences Research, Mayo Clinic, Rochester, MN

#### 22/1323/Culturally Relevant Cancer Risk Counseling for Underserved Latinas

Gloria Juarez, Nursing Research & Education, City of Hope, Duarte, CA, Martin A. Perez, Perez & Associates, A Professiona Clinical Psycholog, None, Pasadena, CA, Veronica I. Lagos, Cilinical Cancer Genetics, Kathleen R. Blazer, Raquel Ogaz, Clinical Cancer Genetics, City of Hope, Duarte, CA, Charite Ricker, Cancer Genetics Program, USC/Norris, Los Angeles, CA, Jeffrey M. Weitzel, Clinical Cancer Genetics, City of Hope, Duarte, CA

23/1109/The Relationship between Weight Loss and Quality of Life in Persons Treated for Head and Neck Cancer Barbara A. Head, Internal Medicine, University of Louisville School of Medicine, Louisville, KY

#### Poster Session 1 - Thursday

#### 24/1505/Developing a disease specific PRO reporting system for patients receiving radiotherapy

Erik K. Fromme, Medicine, Radiation Medicine, and Nursing, Tawni Kenworthy-Heinige, Medicine, Michelle R. Hribar, Medical Informatics and Clinical Epidemiology, Samuel J. Wang, Radiation Medicine, Lillian M. Nail, Karen Lyons, School of Nursing, Susan W. Tolle, Medicine, Charles R. Thomas, Radiation Medicine, Oregon Health & Science University, Portland, OR

### 25/1531/Effects of mood disturbance, fatigue, insomnia, and pain on quality of life of patients receiving cancer therapy

Kin-fong, Karis Cheng, Nursing, The Chinese University of Hong Kong, Shatin, Hong Kong

### 26/1542/Applicability And Characteristics of the New Instrument for Comprehensive Symptom Profile Assessment in Patients with Malignant Lymphomas

Svetlana A. Kalyadina, Symptom Research Dept., Multinational Center for Quality of Life Research, St.Petersburg, Russia, Denis A. Fedorenko, Nikita E. Mochkin, Hematology Dept., National Pirogov Medical Surgical Center, Moscow, Russia, Kira A. Kurbatova, Quality of Life Dept., Multinational Center for Quality of Life Research, St.Petersburg, Russia, Tatyana P. Nikitina, Quality of Life Dept., Multinational Center for Quality of Life Research, Moscow, Russia, Gary Gorodokin, Quality of Life Dept., New Jersey Center for Quality of Life and Health Out, New Jersey, New Jersey, Tatyana I. Ionova, Quality of Life Dept., Multinational Center for Quality of Life Research, St.Petersburg, Andrei A. Novik, Hematology Dept., National Pirogov Medical Surgical Center, Moscow, Russia

### 27/1087/Development and Validation of the System of Quality of Life Instruments for Cancer Patients (QLICP) in China

Chonghua Wan, Jiahong Luo, School of Public Health, Kunming Medical University, Kunming, Yunnan, China, Jun Sui, Head and neck cancer, Xueliang Tang, breast cancer, Canzhen Zhang, lung cancer, Yunnan Tumor Hospital, Kunming, Yunnan, China, Qiong meng, School of public health, Kunming medical university, Kunming, China, Xiaoqing Zhang, zheng yang, School of public health, Kunming medical university, Kunming, Yunnan, China

#### 28/1563/An interpretation strategy for outcomes from the Expanded Prostate Index Composite (EPIC)

Yolanda Pardo, Health research services, IMIM-Hospital del Mar, Barcelona, Spain, Ferran Guedea, Servicio de Oncología Radioterápica., Institut Català dOncologia, Hospitalet de Llobregat, Spain, José Francisco Suárez, SERVICIO DE UROLOGIA, HOSPITAL UNIVERSITARI DE BELLVITGE, L'Hospitalet de Llobregat, Spain, Fernández Pablo, SERVICIO DE ONCOLOGÍA RADIOTERÁPICA, INSTITUTO ONCOLÓGICO DE GIPUZKOA, SAN SEBASTIÁN (GUIPÚZCOA), Spain, Macías Víctor Angel, Servicio de Oncología Radioterápica., Hospital Clínico Universitario de Salamanca, Salamanca, Spain, Mariño Alfonso, O.RADIOTERÁPICA Y MEDICINA NUCLEAR, CENTRO ONCOLÓGICO DE GALICIA, A CORUÑA, Spain, Asunción Hervás, Servicio de Oncología Radioterápica., Hospital Ramon y Cajal, Madrid, Spain, Ismael Herruzo, SERVICIO DE ONCOLOGIA RADIOTERAPICA, HOSPITAL REGIONAL CARLOS HAYA, Málaga, Spain, María José Ortiz, Oncología radioterápica, Hospitales Universitarios Virgen del Rocío, SEVILLA, Spain, Ponce de León Javier, Urología, Nefrología y Andrología, Fundació Puigvert, Barcelona, Spain, Craven-Bratle Jordi, Servicio de Oncología Radioterápica, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain, Ana María Boladeras, Servicio de Oncología Radioterápica, Instituto Catalán de Oncología, Hospitalet de Llobregat, Spain, Àngels Pont, Health Services Research, IMIM - Hospital del Mar, Barcelona, Spain, Adriana Ayala, SERVICIO DE ONCOLOGÍA RADIOTERÁPICA, INSTITUTO ONCOLÓGICO DE GIPUZKOA, SAN SEBASTIÁN (GUIPÚZCOA), Spain, Gemma Sancho, SERVICIO DE ONOCLOGÍA RADIOTERÁPICA, HOSPITAL DE LA SANTA CREU I SANT PAU, BARCELONA, Spain, Evelyn Martínez, Servicio de Oncología Radioterápica, Instituto Catalán de Oncología, Hospitalet de Llobregat, Spain, Montserrat Ferrer, Health Services Research, IMIM-Hospital del Mar, Barcelona, Spain, Multicentric Spanish Group of Clinically Localized P Ca, Health Services Research, IMIM- Hospital del Mar, Barcelona, Barcelona

### 29/1624/Gender and age differences on quality of life and psychopathological symptoms of HIV-infected patients

Marco D. Pereira, Institute of Cognitive Psychology, Maria C. Canavarro, Faculty of Psychology and Educational Sciences, University of Coimbra, Coimbra, Portugal

### 30/1629/Assessing the factor structure and factorial invariance across gender and HIV status of the European Portuguese Version of WHOQOL-HIV-Bref

Marco D. Pereira, Institute of Cognitive Psychology, Maria C. Canavarro, Faculty of Psychology and Educational Sciences, University of Coimbra, Coimbra, Portugal

#### 31/1269/Psychometric evaluation of a new measure of QOL for Chinese people living with HIV/AIDS

C.F. Ho, Nursing, Department of Health, Hong Kong, Hong Kong, Hong Kong, K.K.F. Cheng, S. Twinn, Nursing, The Chinese University of Hong Kong, Hong Kong, Hong Kong Special Administrative Region

#### 32/1124/Quality of Life, Pessimism and Life Satisfaction in HIV Positve People (A study from India)

Selwyn Stanley, Social Work, University of Plymouth, Plymouth, UK, Sethuramalingam V, Sathya S, Social Work, Bharathidasan University, Tiruchirappalli, India

#### 33/1150/Doing research into social participation in people with aphasia: yes, we can!

Ruth J. Dalemans, Dept. Health and Technique, Luc J. de Witte, Centre of expertise on Technology in Care, Zuyd University, Heerlen, the Netherlands, Derick T. Wade, Oxford Centre of Enablement, Oxford Centre of Enablement, Oxford, UK, Wim J. van den Heuvel, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands

### 34/1151/The psychometric properties of the Community Integration Questionnaire adjusted for people with aphasia

Ruth J. Dalemans, Health and Technique, Luc P. de Witte, Centre of expertise on Technology in Care, Anna J. Beurskens, Centre of expertise Autonomy and Participation, Zuyd University, Heerlen, the Netherlands, Wim J. van den Heuvel, Medicine and Life Sciences, Maastricht University, Maastricht, the Netherlands, Derick T. Wade, Oxford Centre of Enablement, Oxford Centre of Enablement, Oxford, UK

#### 35/1425/The importance of guidelines for ClinROs: the ADAS-Cog, a case study

Caroline Anfray, Christelle Giroudet, MAPI Institute, Lyon, France, Catherine Acquadro, MAPI Research Trust, Lyon, France

### 36/1143/Using Novel Information Technology to Assess Baseline Health and Functional Status of Patients with Multiple Sclerosis in a Clincial Population: proof of concept and clinical findings

Deborah M. Miller, Neurology, Erick Novak, Quantiative Health Sciences, Jeffrey A. Cohen, Robert J. Fox, Jennifer Hartman, Kathleen Schwtez, Richard A. Rudick, Neurology, Cleveland Clinic, Cleveland, Ohio

# 37/1411/Using the Liverpool Quality of Life battery to develop a health state classification system for Epilepsy Donna Rowen, Brendan Mulhern, John Brazier, School of Health and Related Research, University of Sheffield, Sheffield, UK, Ann Jacoby, Population, Community and Behavioural Sciences, Tony Marson, Clinical Science, University of Liverpool, Liverpool, UK, Nick Latimer, School of Health and Related Research, University of Sheffield, Sheffield, UK, Dee Snape, Division of Public Health, Gus Baker, Division of Neurosciences, University of Liverpool, Liverpool, UK, Dyfrig Hughes, Centre for Economics and Policy in Health, Bangor University, Bangor, UK

38/1564/Development of a conceptual model of quality of life in care home residents with multiple sclerosis
Afsane Riazi, Siobhan A. Bradshaw, Psychology, Royal Holloway, University of London, Egham, Surrey, UK, E Diane Playford,
Brain Repair and Rehabilitation, Institute of Neurology, Queen Square, London, UK

### 39/1709/Quality of Life in persons with Physical Disabilities caused by neurodegenerative disorders: Using the WHOQOL-DIS

Ramona Lucas-Carrasco, Juana Gomez-Benito, Psychology, U. Barcelona, Barcelona, Spain

#### 40/1353/Cognition and quality of life in multiple sclerosis patients: BRB-N and MusiQoL

Karine Baumstarck-Barrau, Marie-Claude Simeoni, Department of Public Health, Medicine University, Nord University Hospital, Marseille, France, Francoise Reuter, Irina Klemina, Department of Neurology and CRMBM CNRS6612, Timone University Hospital, Marseille, France, Valerie Aghababian, EA 3273 Psychology of Cognition, Language, Aix-Marseille University, Marseille, France, Julie Berbis, Anderson Loundou, Department of Public Health, Medicine University, Nord University Hospital, Marseille, France, Pascal Auquier, Department of Public Health, Medicine University Hospital, Marseille, France

#### 41/1272/Changes and differences in the health-related quality of life among patients undergoing rehabilitation

Ryota Izumi, Shinichi Noto, Occupational Therapy, Niigata University of Health and Welfare, Niigata, Japan, Takamoto Uemura, Public Health, Kyorin University School of Medicine, Tokyo, Japan, Tetsuya Sano, Rehabilitation, Hamamatsu University School of Medicine, Shizuoka, Japan, Eri Kitagawa, Rehabilitation, Kyoritsu Jyuzen Hospital, Shizuoka, Japan, Kazuo Saito, Rehabilitation, Fuchinobe Sogo Hospital, Kanagawa, Japan

### 42/1070/The Construct Validity of the Health Utilities Index Mark 3 (HUI3) in Assessing Health Status in Lung Transplantation

Maria Jose Santana, Lung transplant program, University of Alberta, Edmonton, AB, Canada, David Feeny, Center for Health Research, Kaiser Permanente Northwest, Portland, Oregon, Sunita Ghosh, Experimental Oncology, Cross Cancer Institute, Edmonton, AB, Canada, Roland G. Nador, Justin Weinkauf, Kathleen Jackson, Dale Lien, Lung transplant program, University of Aberta Hospital, Edmonton, AB, Canada

#### 43/1084/Quality of Life in Patients with Microtia Plastic Operation

Toshihiro Saito, Kazuki Maesaka, Atsuhiko Sakamoto, Haruyasu Fujita, Kunio Nakayama, Kozaburo Adachi, Kanehisa Morimoto, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN, Takashi Mandai, (National Cerebral and Cardiovascular Center), ,Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN, Nobuhiko Isshiki, Isshiki Clinic, Karasumadori, Kyoto, Kyoto, JAPAN

#### 44/1712/Associations of Patient vs. Clinician Adverse Event Reports with Functional Status

Thomas M. Atkinson, Psychiatry & Behavioral Sciences, Xiaoyu Jia, Laura Sit, Mike Fruscione, Dawn Lavene, Mary Shaw, Lauren Rogak, Glenn Heller, Ethan Basch, Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, New York

#### 45/1332/Quality of Life Measurement in Chronic Urticaria: A Systematic Review

Delaney A. Bucknor, Psychology, London Metropolitan University, London, UK, Anna H. Baker, Psychology, London Metropolitan University, London, England

#### 46/1461/Measurement Properties of the Urticaria Activity Score (UAS)

Susan D. Mathias, Outcomes Research, Health Outcomes Solutions, Winter Park, FL, Ross D. Crosby, Biomedical Statistics & Methodology, Neuropsychiatric Research Institute, Fargo, ND, James Zazzali, Health Economics & Outcomes Research, Genentech Inc, S San Francisco, CA

#### 47/1562/Relevance of symptoms in end-of-life care

Barbara Antunes, Pedro L. Ferreira, CEISUC, Coimbra, Portugal, Ana B. Pinto, Santa Maria Hospital, Lisboa, Portugal

#### 48/1062/Do PROs Predict what Bothers Patients the Most? "Absolute-ly"

Claire F. Snyder, Medicine, Amanda L. Blackford, Oncology, Johns Hopkins, Baltimore, MD, Neil K. Aaronson, Psychosocial Research & Epidemiology, Netherlands Cancer Institute, Amsterdam, The Netherlands, Symone B. Detmar, Youth, TNO Quality of Life, Leiden, The Netherlands, Michael A. Carducci, Oncology, Johns Hopkins, Baltimore, MD, Michael D. Brundage, Division of Cancer Care and Epidemiology, Queen's Cancer Research Institute, Kingston, ON, Canada, Albert W. Wu, Health Policy & Management, Johns Hopkins, Baltimore, MD

#### 49/1722/Development of the US National Frequent Heartburn Index (HBI) and Associated Composite Score

Donald E. Stull, Patricia de Jonge, Katherine Houghton, United BioSource Corporation, London, UK, Christopher Kocun, Novartis Consumer Health, Inc., Parsippany, NJ, David W. Sandor, Center for Health Outcomes Research, New York, NY

#### Methods & Methodology

#### 50/1639/Response shift which occurred to healthcare provider influenced satisfaction of the service users

Yoshimi Suzukamo, Motoko Tanabe, Shin-ich Izumi, Physical Medicine & Rehabilitation, Tohoku University Graduate School of Medicine, Sendai, Japan

### 51/1243/Response Shift in Quality of Life Measurement among Patients with Hypertension in a Community in China

Hong-Mei Wang, Pan-Pan Liu, Social Medicine and Family Medicine, Zhejiang University, Hangzhou, Zhejiang Province, China, Donald L. Patrick, Todd C. Edwards, Anne M. Skalicky, Health Services, University of Washington, Seattle, WA

#### 52/1220/Understanding Appraisal Processes Underlying the Thentest: A Mixed Methods Investigation

Bruce A. Rapkin, Epidemiology and Population Health, Albert Einstein College of Medicine, Bronx, NY, Carolyn E. Schwartz, Medicine and Orthopaedic Surgery, DeltaQuest Fdn and Tufts U School of Medicine, Concord, MA

#### 53/1314/A Philosophical Explanation of Response Shift

Leah M. McClimans, Philosophy, University of South Carolina, Columbia, SC

#### 54/1382/BiblioPRO: online library of PRO instruments in Spanish

Mireya García-Durán Huet, Health Services, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain, Montserrat Ferrer, Health Services, IMIM-Institut de Recerca Hospital del Mar, CIBERESP, Barcelona, Spain, Michael J. Herdman, Health Services, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain, Juan Ignacio Arrarás, Medical and Radiotherapeuticoncology, Hospital de Navarra, Pamplona, Navarra, Spain, Antonio Escobar, Research Unit, Hospital de Basurto, CIBERESP, Bilbao, Spain, Ana García-Altés, Research Unit, King's College London & London School of Economics, London, United Kingdom, Ramona Lucas, Research Unit, Institut Català de l'Envelliment, Barcelona, Spain, Susana Ochoa, Research Unit, Parc de Salut SJD-SSM, CIBERSAM, Barcelona, Spain, Gaietà Permanyer, Cardiology, University Hospital Vall d'Hebron, CIBERESP, Barcelona, Spain, Jose M. Quintana, Research Unit, Hospital de Galdakao, CIBERESP, Galdakao, Vizcaya, Spain, Luis Rajmil, Health Services, IMIM-Institut de Recerca Hospital del Mar, CIBERESP, Barcelona, Spain, Pablo Rebollo, Scientific, BAP Health Outcomes Research S.L., Oviedo, Asturias, Spain, Aida Ribera, Cardiology, University Hospital Vall d'Hebron, CIBERESP, Barcelona, Spain, Jose M. Valderas, Health Systems and Policies, LSE and CIBERESP, London, United Kingdom, Jordi Alonso, Health Services, IMIM-Institut de Recerca Hospital del Mar, CIBERESP, Barcelona, Spain

### 55/1123/Do SF-36 item scores mean the same for different subgroups of a population? comparing different methods of detecting differential item functioning.

Beth Pollard, MARIE JOHNSTON, Psychology, University of Aberdeen, Aberdeen, Scotland, DIANE DIXON, Psychology, University of Strathclyde, Glasgow, Scotland

### 56/1214/Is it necessary to adapt the UK English original of the Diabetes Treatment Satisfaction Questionnaire(DTSQs) before use in other countries?

Patricia Caire, MAPI Institute, Lyon, France, Rosalind Plowright, Health Psychology Research Ltd, University of London, Egham, Surrey, United Kingdom, Katrin Conway, MAPI Research Trust, Lyon, France, Clare Bradley, Health Psychology Research Ltd, University of London, Egham, Surrey, United Kingdom

### 57/1122/Predictors for satisfaction with activity participation and cultural specific items for Taiwanese with mental illness using longitudinal dataset

Yun-Ling Chen, Ay-Woan Pan, Occupational Therapy, Ping-Chuan Hsiung, Social Work, National Taiwan University, Taipei, Taiwan, Tsyr-Jang Chen, Mechanical Engineering, LungHwa University of Science and Technology, Taipei, Taiwan, LyInn Chung, Statistics, National Taipei University, Taipei, Taiwan, Jung-Der Wang, Occupational Medicine and Industrial Hygiene, Pei-Fan Wu, I-Ting Wang, Occupational Therapy, National Taiwan University, Taipei, Taiwan

### 58/1809/Correlates of Quality of Life: A Cross-cultural Comparison between the United Kingdom and the United States. The Whitehall II Study and the Western New York Health Study

Yim Lun Wong, Health Sciences Research Institute, University of Warwick Medical School, Coventry, West Midlands, UK, Kandala Ngianga-Bakwin, Clinical Sciences Research Institute, University of Warwick, Coventry, West Mildands, United Kingdom, Jane Ferrie, Epidemiology and Public Health, University College London, London, UK, Joan Dorn, Department of Social & Preventive Medicine, State University of New York at Buffalo, Buffalo, Mika Kivimäki, Epidemiology and Public Health, University College

London, London, UK, Richard P Donahue, Department of Social & Preventive Medicine, State University of New York at Buffalo, New York, Archana Singh-Manoux, Department of Epidemiology and Public Health, University College London, London, UK, Jo Freudenheim, Department of Social & Preventive Medicine, State University of New York at Buffalo, NY, Eric J Brunner, Epidemiology and Public Health, University College London, London, UK, Maurizio Trevisan, Health Sciences System of the Nevada System of Highe, Health Sciences System of the Nevada System of Highe, Las Vegas, Saverio Stranges, Health Sciences Research Institute, University of Warwick Medical School, Coventry, West Midlands, United Kingdom

#### 59/1663/Cross-cultural Comparisons:Lessons from Friedreich's Ataxia

Roderick G. Freeman, Stefan Cano, Anita Slade, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, Devon, UK, Martin Delatycki, Department of Medicine, University of Melbourne, Heidelberg, Victoria, Australia, Geneieve Tai, Bruce Lefroy Centre for Genetic Health Research, Murdoch Childrens Research Institute, Parkville, Victoria, Australia, Jeremy Hobart, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, Devon, UK

#### 60/1796/Quality of life after a heart attack: East vs West

Johana Nayoan, Research Centre for Society & Health, Buckinghamshire New University, High Wycombe, Buckinghamshire, UK

### 61/1418/Recommendations about Translations in the final FDA Guidance on PRO Measures: What has changed and what has remained

Katrin Conway, Managing Director, MAPI Research Trust, Lyon, France, Isabelle Méar, Linguistic Validation, MAPI Institute, Lyon, France

#### 62/1540/Measurement Invariance of the SAMHSA Mental Health and Alcohol Abuse Stigma Assessment

Bellinda L. King-Kallimanis, Frans J. Oort, Medical Psychology, AMC University of Amsterdam, Amsterdam, The Netherlands, Nancy Lynn, Lawrence Schonfeld, Aging and Mental Health Disparities, University of South Florida, Tampa, Florida

#### 63/1543/Validation Research Results of the Japanese version of the WHOQOL

Miyako Tazaki, Medicine, Toho University, Tokyo, Japan, Yoshibumi Nakane, Medicine, Nagasaki University, Nagasaki-shi, Japan

#### 64/1549/Use and value of back translation review in the translation of PROMs

Diane J. Wild, Tamzin Furtado, Translation and Linguistic Validation, Oxford Outcomes, Oxford, Oxon, UK

### 65/1357/Self-Rated Health: Alternative Translations OF RESPONSE CATEGORIES APPLIED IN THE SAME GROUP OF STUDENTS

Joanna Mazur, Anna Dzielska, Izabela Tabak, Hanna Kololo, Child and Adolescent Health, Institute of Mother and Child, Warsaw, Poland

### **Population & Policy**

#### 66/1282/Urban health-related quality of life: do municipal services matter?

Faranak Farzadi, Health Services Management, Ali Montazeri, Mental Health, Jila Sadighi, Family Health, Mariam Vahdaninia, Social Medicine, Afsoon Aeenparast, Health Services Management, Institute for Health Sciences Research, ACECR, Tehran, Iran

#### 67/1280/Urbah health-related quality of life: does the place of living matter?

Ali Montazeri, Mental Health, Faranak Farzadi, Health Services Management, Mariam Vahdaninia, Social Medicine, Sepideh Omidvari, Mental Health, Institute for Health Sciences Research, ACECR, Tehran, Iran

#### 68/1570/Impact of influenza A (H1N1/2009) infection on quality of life and health services

Olatz Garin, Health Services Research Group, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain, Mariana Galante, Montse Ferrer, Health Services Research Unit, IMIM-Hospital del Mar, Barcelona, Spain, Elisa Sicuri, Health Economics, Barcelona Center for International Health Research, Barcelona, Spain, Anna García-Altés, Division of Health and Social Care Research, King's College London, London, UK, Manel Nebot, Agencia de Salud Pública de Barcelona, Barcelona, Spain, Angela Dominguez, CIBER DE EPIDEMIOLOGÍA Y SALUD PÚBLICA, Barcelona, Spain, Jordi Alonso, Health Services Research Unit, IMIM-Hospital del Mar, Barcelona, Spain

### 69/1360/The impact of quality of life and other patient characteristics on health care use in patients with congenital heart disease

Dounya Schoormans, Medical Psychology, Academic Medical Centre, Amsterdam, The Netherlands, Barbara J. Mulder, Cardiology, Academic Medical Centre, Amsterdam, Netherlands, Mirjam A. Sprangers, Medical Psychology, Academic Medical Centre, Amsterdam, Amsterdam

### 70/1290/Similarities and differences in the meaning of "Quality of Life". An Information Integration study with similar but culturally distinct groups.

Peter Theuns, Psychology and Education Sciences, Vrije Universiteit Brussel, Brussel, -, Belgium

#### 71/1274/Quality of Life Deterioration by Pandemic Panic Influenza Viral Infection

Takashi Mandai, Japanese Society of Quality of Life Research,, (National Cerebral and Cardiovascular Center), Kobe, Hyogo, Japan, Toshihiro Saito, Kazuki Maesaka, Atsuhiko Sakamoto, Shoudou Hirano, Yousuke Nishioka, Munehiro Ashida, Toru Sumiyoshi, Mitsuhiro Masuda, Wataru Sato, Ichiro Nagano, Sachiko Takeuchi, Haruyasu Fujita, Kunio Nakayama, Satoshi Ogino, Kozaburo Adachi, Kanehisa Morimoto, Japanese Society of Quality of Life Research, Kobe, Hyogo, JAPAN

#### 72/1509/The New Zealand version of the WHOQOL-BREF: Confirming the factor structure and making multigroup comparisons

Christian U. Krägeloh, Rex Billington, Patricia Hsu, Penny Chai, Daniel Shepherd, Jason Landon, Psychology, Auckland University of Technology, Auckland, New Zealand

### 73/1781/Longitudinal response in the agricultural community - Lessons from the Regional Rural Injury Study-III (RRIS-III)

Colleen M. Renier, Division of Research, Essentia Institute of Rural Health, Duluth, MN, Susan G. Gerberich, Patricia M. McGovern, Bruce H. Alexander, Timothy R. Church, Steven J. Mongin, Andrew D. Ryan, Environmental Health Sciences, Ann S. Masten, Institute of Child Development, University of Minnesota, Minneapolis, MN

#### 74/1257/The Development and Validation of a Sub-health Questionnaire (SHQ)

Wenwei Huang, Family Medicine Unit, Department of Medicine, Cindy Lam, Family Medicine Unit, The University of Hong Kong, Hong Kong, China

#### 75/1789/CVT-GOHISALO Questionnaire to measure Quality of Work Life, "Validation".

Raquel Gonzalez, Instituto de Investigación en Salud Ocupacional, GUSTAVO HIDALGO, Fisiología, JOSE G. SALAZAR, LOURDES PRECIADO, Instituto de Investigación en Salud Ocupacional, BRENDA J. HIDALGO, Escuela de Psicología, Universidad de Guadalajara, Guadalajara, Jalisco, México

### 76/1576/Health related quality of life in patients with chronic obstructive pulmonary disease-a comparison with general population norms

Signe Berit Bentsen, Health Education, Stord/Haugesund University College, Haugesund, Norway, Berit Rokne, Department of Public Health and Primary Care, University of Bergen, Bergen, Norway, Eva Langeland, Department of Social Education and Social Work, Bergen University College, Bergen, Norway, Astrid K. Wahl, Department of Nursing and Health Science, University of Oslo, Oslo, Norway

#### 77/1245/Factorial invariance of the SF-36 among disease groups

Grace Yao, Psychology, National Taiwan University, Taipei, Taiwan, ROC, Wei-Ling Lin, Psychology, National Taiwan University, Taipei, Taiwan

### 78/1593/Haemophilc Patiemnts Health Related Quality of Life: Relationships Between Generic and Disease Dimensions

Marie-Line Erpelding, Lucie GERMAIN, Epidémiologie et Evaluation Cliniques, CHU Nancy, Nancy, France, Hervé CHAMBOST, Centre de Traitement de l'Hémophilie, CHU Timone, AP-HM, Marseille, France, Florence SUZAN, Alexandra DONCARLI, Virginie DEMIGUEL, Centre coordinateur du Réseau FranceCoag, InVS, http://www.francecoag.org, Saint-Maurice, France, Thierry LAMBERT, Centre de Traitement de l'Hémophilie, CHU Kremlin-Bicêtre, AP-HP, Le Kremlin-Bicêtre, France, Claude GUEROIS, Centre de Traitement de l'Hémophilie, CHRU de Tours, Tours, France, Juliette BLOCH, Dpt. des maladies chroniques et des traumatismes, InVS, Saint-Maurice, France, Serge BRIANÇON, EA4360 Apemac-Epidémiologie et Evaluation Cliniques, CHU Nancy, Nancy, France

#### 79/1244/Life enjoyment and cause-specific mortality among men and women: The Japan Collaborative Cohort Study

Mariko Naito, Preventive Medicine, Nagoya University Graduate School of Medicine, Nagoya, Aichi, Japan, Kiyomi Sakata, Hygiene and Preventive Medicine, Iwate Medical University School of Medicine, Morioka, Iwate, Japan, Akiko Tamakoshi, Public Health, Aichi Medical University School of Medicine, Nagakute, Aichi, Japan

#### 80/1129/Psychological Correlates and Quality of Lifeof HIV Infected Persons (A study from India)

Sethu Ramalingam, Social Work, Bharathidasan University, TIRUCHIRAPPALLI, Tamil Nadu, India, selwyn Stanley, School of Psychosocial Studies, University of Plymouth, Drake Circus, Devon, UK, sathia s. Suthanthiraveeran, Social Work, Bharathidasan University, TIRUCHIRAPPALLI, Tamil Nadu, INDIA

#### 81/1632/Quality of Life & Socio-demographic Characteristics

Norma A. Ruvalcaba, Departamento de Clínicas de Salud Mental, José G. Salazar, Salud Pública, Universidad de Guadalajara, Guadalajara, Jalisco, México, Pablo Fernández-Berrocal, Psicología Básica, Universidad de Málaga, Málaga, Andalucia, España

#### 82/1646/Health-Related Quality of Life and Sociodemographic characteristics in High School students

Joseph Benie Bi, Emilie BONSERGENT, Sabrina TESSIER, Serge Briançon, EA 4360 Apemac, Nancy University, NANCY, France

### 83/1729/Differential Item Functioning in the Center for Epidemiological Studies Depression between English and Spanish versions in a Latino Cohort

Sylvia H. Paz, Health Services, University of California, Los Angeles, La Canada, CA, Leo S. Morales, Group Health Research Institute, Seattle, WA, Honghu Liu, Medicine, University of California, Los Angeles, CA, Rohit Varma, Ophthalmology, University of Southern California, Los Angeles, CA, Ron D. Hays, Medicine, University of California, Los Angeles, Los Angeles, CA

#### 84/1208/Paranoid ideation: predictor of Quality of Life?

Adrian Coxell, Victoria L. Mason, Gemma Mallett, Psychological Sciences, University of Worcester, Worcester, UK

### 85/1437/The Use of mixed method to study the psychometric qualities of the unsupported social interactions inventory

Ay-Woan Pan, Occupational Therapy, Ping-Chuan Hsiung, Social Work, National Taiwan University, Taipei, Taiwan, Tsyr-Jang

Chen, Mechanical Engineering, LungHwa University of Science and Technology, Taipei, Taiwan, I-Ting Wang, Yun-Ling Chen, Pei-Fan Wu, Occupational Therapy, National Taiwan University, Taipei, Taiwan

#### 86/1449/The KIDSCREEN to Assess Quality of Life of Adolescents with Autism Spectrum Disorders

Emily N. Neger, R. Christopher Sheldrick, Pediatrics, Floating Hospital for Children, Tufts Medical Center, Boston, MA, Deborah Shipman, Pediatrics, Fallon Medical Center, Leominster, MA, Ellen C. Perrin, Pediatrics, Floating Hospital for Children, Tufts Medical Center, Boston, MA

### 87/1358/The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL): development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia

Laurent Boyer, Department of Public Health, University Hospital Marseille (AP-HM), Marseille, France, Raphaelle Richieri, Psychiatry, Anderson Loundou, Julie Berbis, Public Health, University Hospital Marseille, Marseille, France, Pascal Auquier, Public Health, Christophe Lancon, Psychiatry, Marie-Claude Simeoni, Public Health, University Hospital Marseille, Marseille, 13005, France

#### 88/1108/Health-Related Quality of Life among Greek adults: Obesity-related predictors

Eleni Theodoropoulou, Georgios Nassis, Maria Koskolou, Konstantinos Karteroliotis, Physical Education and Sports Science, National and Kapodistrian University of Athens, Athens, Greece

### 89/1147/Bodyweight, Gender, and Health-Related Quality of Life: Results from a National Longitudinal Survey of Canadian Adults

David Feeny, Center for Health Research, Kaiser Permanente Northwest, Portland, OR, Rochelle Garner, Amanda Thompson, Julie Bernier, Health Analysis Division, Statistics Canada, Ottawa, ON, Canada, Bentson H. McFarland, Psychiatry, Oregon Health & Science University, Portland, OR, Nathalie Huguet, Mark S. Kaplan, School of Community Health, Portland State University, Portland, OR, Nancy Ross, Geography, McGill University, Montreal, QC, Canada

### 90/1599/Personal factors associated with Health Related Quality of Life in patients attending patient education courses while waiting for Bariatric Surgery.

Randi Andenæs, Nursing, Oslo University College, Oslo, Norway, Anners Lerdal, Research Centre, Eva Bjørnsborg, LMS Centre, Tore Bonsaksen, Research Centre, Oslo University Hospital, Aker, Oslo, Norway, Lisbeth Borge, Nursing, Diakonhjemmet University College, Oslo, Norway, Bjørg Christiansen, Hilde Eide, Nursing, Oslo University College, Oslo, Norway, Kari Hvinden, Glittreklinikken, Hakadal, Norway, May Solveig Fagermoen, Research Centre, Oslo University Hospital, Aker, Oslo, Norway

#### 91/1267/Changes in body mass index and change in obesity-related quality of life in working adults

Shirley A A. Beresford, Stephanie A. Whisnant, Epidemiology, Donald L. Patrick, Health Services, University of Washington, Seattle, Washington

### 92/1350/Quality of life, weight perception and weight control behavior by gender in Mexican adolescent students

Carlos A. Hidalgo-Rasmussen, Culture Arts and Humanities, University of Guadalajara, Cd. Guzmán, Jalisco, México, Alfredo R. Hidalgo-San Martín, Jocotepec, Jalisco, México, Bettylú D. Rasmussen-Cruz, Instituto Mexicano del Seguro Social, Jocotepec, Jalisco, México, Rosa Montaño-Espinoza, Ñuñoa, Santiago, Chile

### 93/1401/The Relationship of Body Mass Index and Health-Related Quality of Life Among Factory Workers: a Pilot-Study

Ricardo M. Massola, Rodrigo F. Rio Branco, Juliana F. Valério, Christianne V. Affonso, Roberto Vilarta, Physical Education, Universidade Estadual de Campinas, Campinas, SP, Brazil

#### 94/1292/Parenting practices as predictors of mental health of adolescents with different body mass index

Izabela Tabak, Anna Oblacinska, Maria Jodkowska, Joanna Mazur, Child and Adolescent Health, Institute of Mother and Child, Warsaw, Poland

#### 95/1322/Weight-related self perceptions in people with type 2 diabetes who are obese

Michael L. Meldahl, Global Health Outcomes, David R. Nelson, Global Statistical Sciences, Risa P. Hayes, Global Health Outcomes, Eli Lilly & Company, Indianapolis, Indiana

#### 96/1541/Omega-3 consumption and quality of life: real or marketing effect?

Clotilde Latarche, EA 4360 APEMAC, Nancy-University, Vandoeuvre-lès-Nancy, France, Marie-Line ERPELDING, Epidémiologie et Evaluation Cliniques, CHU Nancy, Vandoeuvre-lès-Nancy, FRANCE, Emmanuelle KESSE-GUYOT, UREN, Université Paris 13, Bobigny, FRANCE, Pilar GALAN, Serge HERCBERG, UREN, Université de Paris 13, Bobigny, FRANCE, Serge BRIANÇON, EA 4360 APEMAC, Nancy-University, Vandoeuvre-lès-Nancy, FRANCE

### 97/1284/To survey young stem cell transplanted (SCT) patients HRQOL as an intergrated part of the comprehensive care program, can this affect the planning of follow-up care?

Catharina M. Löf, Pediatrics, CLINTEC Karolinska Institutet, Stockholm, Sweden, Ulla Forinder, Social Work, Stockholm University, Stockholm, Sweden, Jacek Winiarski, Pediatrics, CLINTEC Karolinska Institute, Stockholm, SWEDEN

#### 98/1653/Conceptualizing Quality of Life in Children with Cancer and Childhood Cancer Survivors

Anne F. Klassen, Aalia F. Khan, Samantha Anthony, Pediatrics, McMaster University, Hamilton, Ontario, Canada, Robert Klaassen, Pediatrics, Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada, Lillian Sung, Pediatrics, Hospital for Sick Children, Toronto, Ontario, Canada

### 99/1771/Solving the Conceptual Discontinuity Problem for Instruments used in Childhood Cancer Research: A systematic review & content analysis using the ICF-CY & WHO definitions

Nora Fayed, Rehabilitation Science, McMaster University, Hamilton, ON, Canada, Vero Schiariti, Pediatrics, University of British Columbia, Vancouver, British Columbia, Canada, Anne Klassen, Pediatrics, McMaster University, Hamilton, ON, Canada

### 100/1455/Measuring Transition Readiness in Childhood Cancer Survivors: Development of a Patient Reported Outcome (PRO) Instrument

Leila Amin, Rehabilitation Science, Anne Klassen, Pediatrics, McMaster University, Hamilton, Ontario, Canada, Paul Nathan, Hematology/Oncology, The Hospital for Sick Children, Toronto, Ontario, Canada, Zahava Rosenberg-Yunger, Leeat Granek, Pediatrics, McMaster University, Hamilton, Ontario, Canada, Norma D'Agostino, Psychosocial Oncology, Princess Margaret Hospital, Toronto, Ontario, Canada, Katherine Boydell, Psychology, The Hospital for Sick Children, Toronto, Ontario, Canada, David Hodgson, Radiation Oncology, Princess Margaret Hospital, Toronto, Ontario, Canada, Ronald Barr, Hematology/Oncology, McMaster Children's Hospital, Hamilton, Ontario, Canada

### 101/1569/Development and validation of a questionnaire measuring quality of life (QOL) in the parents of children treated for acute leukaemia (AL)

Patricia Minaya, Pascal Auquier, Public Health, Nord University Hospital, Marseille, France, Gérard Michel, Pediatrics Hematology, La Timone University Hospital, Marseille, France, Julie Berbis, Marie Claude Simeoni, Public Health, Nord University Hospital, Marseille, France

### 102/1587/French Cohort of Childhood Leukaemia Survivors: Impact of Haematopoietic Stem Cell Transplantation (HSCT) on Health Status and QOL

Julie Berbis, Marie-Claude Simeoni, Public Health, Nord University Hospital, Marseille, France, Gérard Michel, Paediatrics Haematology, La Timone University Hospital, Marseille, France, Pierre Bordigoni, Pascal Chastagner, Audrey Contet, Paediatrics Haematology, University Hospital, Nancy, France, Nicolas Sirvent, Marilyne Poirée, Paediatrics Haematology, University Hospital, Nice, France, François Demeocq, Justyna Kanold, Paediatrics Haematology, University Hospital, Clermont-Ferrand, France, Dominique Plantaz, Paediatrics Haematology, University Hospital, Grenoble, France, Karine Baumstark, Pascal Auquier, Public Health, Nord University Hospital, Marseille, France

### 103/1359/Long-term survivors of childhood cancer report quality of life and health status in parity with a comparison group

Kay K. Sundberg, Claudia Lampic, Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden, Johan Arvidson, Women and Childrens' Health, Uppsala University, Uppsala, Sweden, Eva Doukkali, Lars E. Eriksson, Lena Wettergren, Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden

#### 104/1804/Innovative media for quality of life of Thai children with terminal cancer

Tippakorn Rungkasiri, SURACHAI PRASERTSARUAY, EDUCATIONAL TECHNOLOGY, KASETSART UNIVERSITY, BANGKOK, THAI-LAND

Poster Session 2 Friday, October 29 Viscount Suite and Foyer

Poster numbers 105 through 208

#### Clinical Practice & Research

### 105/1330/The Value of Quality of Life Information to Hormone Refractory Prostate Cancer Patients Facing Treatment Decisions

Brenda H. Bass, Cancer Care and Epidemiology, Queen's- Cancer Research Institute, Kingston, Ontario, Canada, Richard Gregg, Chris Booth, Medical Oncology, Cancer Centre of Southeastern Ontario, Kingston, Ontario, Canada, Michael D. Brundage, Cancer Care and Epidemiology, Queen's -Cancer Research Institute, Kingston, Ontario, Canada

#### 106/1299/Comparative-effectiveness of surgical approaches for robotic prostatectomy

Brent K. Hollenbeck, Rodney L. Dunn, Jeff S. Montgomery, John T. Wei, David P. Wood, Urology, University of Michigan, Ann Arbor, MI

#### 107/1649/Participation in Cervical Cancer Screening and Quality of Life, a Longitudinal Study

Ida J. Korfage, Marjolein van Ballegooijen, Public Health, Erasmus MC, Rotterdam, the Netherlands, Brendy Wauben, Comprehensive Cancer Centre Limburg, National cervical cancer screening program, Maastricht, the Netherlands, Dik Habbema, Public Health, Erasmus MC, Rotterdam, the Netherlands, Marie-Louise Essink-Bot, Social Medicine, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands

#### 108/1633/Genetic Risk Factors and Quality of Life in Colorectal Cancer Patients is there a Correlation?

Thomas Kuechler, Reference Center for quality of life in oncology, University hospital of Schleswig Holstein (UK S-H), Kiel, Schleswig-Holstein, Germany, Clemens Schafmayer, Dep. of General and Thoracic Surgery, University hospital of Schleswig Holstein (UK S-H), Kiel, Germany

### 109/1268/Early and late quality of life recovery after surgery for endometrial cancer: results from a randomised trial (LACE)

Monika Janda, School of Public Health, Queensland University of Technology, Kelvin Grove, Brisbane, QLD, Australia, Val Gebski, NHMRC Clinical Trials Centre, University of Sydney, Camperdown, NSW, Australia, Andreas Obermair, Queensland Centre for Gynaecologic Oncology, Royal Brisbane and Women's Hospital, Herston, QLD, Australia, for the LACE trial investigators

### 110/1554/Integrating health-related quality of life (HRQL) and clinical data to inform decision making: a systematic review of reporting in randomised controlled trials (RCTs) in gastrointestinal cancer (GI)

Rhiannon C. Macefield, Social Medicine, University of Bristol, Bristol, UK, Angus G. McNair, Natalie Blencowe, Sara T. Brookes, Jane M. Blazeby, Social Medicine, University of Bristol, Bristol, United Kingdom

#### 111/1810/Quality of Life in members of prostate cancer support groups

Beate Bestmann, Scientific Inst.for Benefit&Efficiency in Healthcare, Techniker Krankenkasse, Hamburg, Germany, Thomas Kollakowski, DOCXCELLENCE GmbH, DOCXCELLENCE GmbH, Berlin, Germany, Lothar Weissbach, Stiftung Maennergesundheit, Stiftung Maennergesundheit, Berlin, Germany

### 112/1219/Psychometric Evaluation of a 6-Item Short Form of the Female Sexual Function Index (FSFI) in a Sample of Cancer Survivors

Raymond E. Baser, Epidemiology and Biostatistics, Jeanne Carter, Psychiatry and Behavioral Sciences, Yuelin Li, Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, New York, NY

### 113/1457/Five year Expanded Prostate cancer Index Composite (EPIC) based quality of life outcomes after prostatectomy for localized prostate cancer

David P. Wood, Jr., Walter Parker, Chang He, Rou Wang, Urology, University of Michigan, Ann Arbor, MI

#### 114/1750/Health Related Quality of Life of Women with Cervical Cancer

Wanessa C. Fernandes, Miako Kimura, Medical Surgical Nursing, University of Sao Paulo, Sao Paulo, Sao Paulo, Brazil

### 115/1561/Health Related Quality of Life of Nursing Professionals and Medications Erros in Intensive Care Units Josikélem da Silva S. Pelliciotti, Miako Kimura, Nursing, University of Sao Paulo, Sao Paulo, Sao Paulo, Brazil

#### 116/1278/New QOL Questionnaire Development for Chief Nursing Officers

Fumiko Utsumi, Kwassui Women's College, Omura, NAGASAKI, Japan, Michiko Ujita, Nishisonogi-gun, NAGASAKI, JAPAN, Michiko Kobayashi, Kwassui Women's College, Omura, NAGASAKI, JAPAN

### 117/1486/The role of information on discharged patients

Antonio P. Mendes, Coimbra, Portugal, Pedro L. Ferreira, ČEISUC, University of Coimbra, Coimbra, Portugal, Isabel R. Fernandes, Regina R. Ferreira, Portuguese Oncology Institute, Coimbra, Portugal

#### 118/1791/Results According to Gender in the Evaluation of the Quality of Work Life in Health Care Providers

Gustavo Hidalgo, Fisiología, RAQUEL GONZALEZ, SILVIA G. LEON, JOSE G. SALAZAR, Instituto de Investigación en Salud Ocupacional, GRISELDA P. HIDALGO, Hospital Civil Juan I. Menchaca, Universidad de Guadalajara, Guadalajara, Jalisco, México

#### 119/1500/The quality of life from the perspective of students in health sciences

Jose G. Salazar, TERESA M. TORRES L, PUBLIC HEALTH, UNIVERSIDAD DE GUADALAJARA, GUADALAJARA, JALISCO, MEXICO

### 120/1232/Health Related Quality of Life of Kidney Living Donors: Development of a Course Donation Questionnaire

Serge Briancon, EA 4360 APEMAC-Epidémiologie Evaluation Cliniques, GERMAIN Lucie, Epidémiologie Evaluation Cliniques, BAUMANN Cédric, EA 4360 APEMAC-Epidémiologie Evaluation Cliniques, CHU Nancy, Vandoeuvre les Nancy, France, MULLER Laurent, EA 4360 APEMAC- Psychologie de la santé, Université Paul Verlaine, Metz, France, KESSLER Michèle, Nephrologie, CHU Nancy, Vandoeuvre les Nancy, France, NOEL Christian, Néphrologie, CHRU de Lille, Lille, France, THUONG Marie, Direction médicale et scientifique, Agence de la biomédecine, Saint Denis la Plaine Cedex, France, BAUDELOT Christian, Sociologie, Ecole Normale Supérieure, ParisV, France, CAILLE Yvanie, conseil d'orientation, Agence de la biomédecine, Saint Denis la Plaine Cedex, France

#### 121/1130/Quality of Life in Patients with Total Hip and Knee Arthroplasty

Yoshiko Kajiwara, Shigenori Yoshitake, Health Sciences, Kyusyu University of Health and Welfare, Nobeoka, Miyazaki, Japan, Ryoko Uchiyama, Kiyoko Tohuku, Hiroaki Kiya, Nobuhiro Sato, Atago, Orthopedic Hospital, Nobeoka, Miyazaki, Japan, Takashi Mandai, (National Cerebral and Cardiovascular Center), Japanese Society of Quality of Life Research, Kobe, Hyogo, Japan

### 122/1315/The Role of a Workplace Physiotherapy Pain Management Program in Musculoskeletal Pain and Compensation Days

Ricardo M. Massola, Rubens Falleiros, Roberto Vilarta, Physical Education, Universidade Estadual de Campinas, Campinas, SP, Brazil

### 123/1105/A Test-retest Reliability Study of the Whiplash Disability Questionnaire (WDQ) in Patients with Recent Whiplash-Associated Disorders (WAD)

Maja Stupar, Health Policy, Management and Evaluation, University of Toronto, Toronto, ON, Canada, Pierre Côté, Toronto Western Research Institute, University Health Network, Toronto, ON, Canada, Dorcas Beaton, Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada, Eleanor Boyle, J David Cassidy, Toronto Western Research Institute, University Health Network, Toronto, ON, Canada

### 124/1403/Differences in the Health Related Quality of life of Amathic patients according to the illness classification

Juliana Maria S. Pinto, Ana María M. Nogueras, Physiotherapy, Jacinto R. González, Medicine, Jose Ignacio C. Arenillas, Physiotherapy, University of Salamanca, Salamanca, Salamanca, Spain

#### 125/1074/Using the SF-36 Sub-Scales as a Composite Outcome to Evaluate a Complex Intervention

Nancy E. Mayo, Medicine, McGill University Health Centre, Montreal, QC, Canada, Susan C. Scott, Clinical Epidemiology, McGill University Health Centre, Montreal, QC, Canada

### 126/1366/Implementation of measurement instruments in physical therapist practice: development of a tailored strategy

Anna J. Beurskens, Anita Stevens, Autonomy and Participation for chronic patients, Zuyd University for applied sciences, Heerlen, The Netherlands, Roland P. van Peppen, Physical Therapy, Harriet Wittink, Innovations in Health Care, Utrecht University of applied sciences, Utrecht, The Netherlands, Jan W. Custers, Royal Dutch Society of Physical Therapy, Amersfoort, The Netherlands, Raymond A. Swinkels, Autonomy and Participation for chronic patients, Zuyd University for applied sciences, Heerlen, The Netherlands

#### 127/1013/Factors Associated with Quality of Life in Patients with Heart Failure

Chantira Chiaranai, Institute of Nursing, Suranaree University of Technology, Muang, Nakhonratchasima, Thailand

#### 128/1390/Cultural adaptation and validation of Ostomy Adjustment Inventory-23 (OAI-23) for Brazilians

Vera L. Santos, Camila C. Nascentes, Maria E. Silva, Marilice W. Oliveira, Herica D. Dias, Miako Kimura, Nursing School, University of São Paulo, São Paulo, São Paulo, Brazil, Kingsley Simmons, School of Nursing and Midwifery, University of Hertfordshire, Hatfield, Hertfordshire, United Kingdom

### 129/1398/Cultural adaptation of City of Hope Quality of Life Ostomy Questionnaire (COH-QOL-OQ) for Brazilians Gustavo Gomboski, Vera L. Santos, Nursing School, University of São Paulo, São Paulo, São Paulo, Brazil

#### 130/1476/Work, Job Satisfaction and Quality of Life

João P. Pereira, Maria J. Cunha, Andreia D. Sousa, Ludovina S. Azevedo, Cecilia Loureiro, Psychology, Instituto Superior da Maia, Avioso S. Pedro, Portugal, Pedro Lopes, Medicine, Faculdade de Medicina da Universidade de Coimbra, Coimbra, Portugal

#### 131/1567/The local environment and quality of life: focusing on individuals with disabilities

Debbie Hart, Institute of Social and Economic Research, University of Essex, Colchester, Essex, UK

### 132/1667/Factors contributing to Good Quality of Life for people who live in Care Homes: A Thematic Synthesis

Siobhan A. Bradshaw, Psychology, Royal Holloway, University of London, Egham, Surrey, England, Diane Playford, Brain Repair and Rehabilitation, Institute of Neurology, Queen Square, London, England, Afsane Riazi, Psychology, Royal Holloway, University of London, Egham, Surrey, England

### 133/1381/Utilizing the theory of planned behavior to understand how exercise affects lower limb disabilities quality of life.

Hung Ru Chen, Kai-Ping Yao, Psychology, National Taiwan University, Taipei, Asian, Taiwan

### 134/1689/Fatigue in Spinal Cord Injury (SCI), Muscular Dystrophy (MD), Post-Polio Syndrome (PPS) and Multiple Sclerosis (MS): Age Group Comparisons to U.S. Norms

Karon F. Cook, Rehabilitation Medicine, University of Washington, Seattle, Houston, TX

#### 135/1395/Development of an Excessive Sleepiness Diary

Josephine M. Norquist, Epidemiology, Merck Sharp & Dohme, Corp., North Wales, PA, Margaret K. Vernon, United BioSource Corporation, Bethesda, MD, Sean OQuinn, Bethesda, MD, Kelly McQuarrie, United BioSource Corporation, Bethesda, MD, David F. Dinges, Philadelphia, PA, Tom Roth, Detroit, MI, William J. Herring, Clinical Neuro & Ophthalmology, Kimberly G. Brodovicz, Epidemiology, Merck Sharp & Dohme, Corp., North Wales, PA

### 136/1273/A randomized controlled cross-over clinical trial using oral appliances in the management of obstructive sleep apnoea

Colman McGrath, Dentistry, The University of Hong Kong, Hong Kong, Hong Kong, Hong Kong, Anika Ahrens, Dentistry, The Faculty of Hong Kong, Hong Kong, Hong Kong, Hong Kong, Hong Kong

# 137/1710/Developing New Outcome Measures for Fatigue and Quality of Life in People with Spinal Damage Julian G. Yeh, Neurology, University of Liverpool, Liverpool, UkUK, Carolyn A. Young, Neurology, Walton centre for neurology and neurosurgery, Liverpool, UK

### 138/1400/Work in Progress: Developing and validating self report measures for fatigue and need-based quality of life in Post Polio Syndrome (PPS)

Samantha M. Wong, Clinical Trials Unit, Walton Centre for Neurology and Neurosurgery, Fazakerley, Liverpool, UK, Anne-Marie C. Quincey, Clinical Trials Unit, Carolyn A. Young, Neurology, Walton Centre for Neurology and Neurosurgery, Fazakerley, Liverpool, England

#### 139/1657/Does a Rasch-modified FSS deliver better measurements?

Anita L. Slade, John P. Zajicek, Wendy M. Ingram, Roderick G. Freeman, Stefan Cano, Jeremy C. Hobart, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, Devon, UK

#### Methods & Methodology

### 140/1559/Patient-reported outcomes in Chronic Myeloid Leukemia: what do we know? A systematic review from 1980 to 2010

Massimo Breccia, Department of Hematology, University of Rome La Sapienza, Rome, Italy, Fabio Efficace, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy, Kim Cocks, Clinical Trials Research Unit, University of Leeds, Leeds, UK, Mirjam Sprangers, Department of Medical Psychology, University of Amsterdam, Amsterdam, Netherlands, Marco Vignetti, Franco Mandelli, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy

#### 141/1526/Factors affecting overall quality of life in untreated patients with hematological malignancies

Fabio Efficace, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy, Gianluca Gaidano, Division of Hematology, University of Eastern Piedmont Amedeo Avogadro, Novara, Italy, Maria Teresa Voso, Department of Hematology, University of Rome, Cattolica S. Cuore, Rome, Italy, Mirjam Sprangers, Department of Medical Psychology, University of Amsterdam, Amsterdam, Netherlands, Massimo Breccia, Department of Hematology, University of Rome La Sapienza, Rome, Italy, Giovanni Caocci, Centro Trapianti Midollo Osseo, Hospital Binaghi, Cagliari, Italy, Emanuele Angelucci, Department of Hematology, Hospital Businco, Cagliari, Italy, Monia Lunghi, Division of Hematology, University of Eastern Piedmont Amedeo Avogadro, Novara, Italy, Marianna Criscuolo, Department of Hematology, University of Rome, Cattolica S. Cuore, Rome, Italy, Anna A. Di Tucci, Department of Hematology, Hospital Businco, Cagliari, Italy, Nicola Cascavilla, Department of Hematology, Hospital Casa Sollievo della Sofferenza, S. Giovanni Rotondo, Italy, Giorgina Specchia, Division of Hematology, University of Bari, Bari, Italy, Silvana Capalbo, Department of Hematology, Azienda Ospedaliero-Universitaria Ospedali Riuniti, Foggia, Italy, Francesco Cottone, Marco Vignetti, Franco Mandelli, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases, GIMEMA, Rome, Italy

### 142/1407/Patient-Reported Outcome Instruments Used to Assess Pain and Functioning in Studies of Treatment for Bone Metastases

Louis S. Matza, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD, Lesley Fallowfield, Cancer Research UK, University of Sussex, Falmer, Brighton, UK, Karen Chung, Global Health Economics, Amgen, Inc, Thousand Oaks, CA, Brooke M. Currie, Center for Health Outcomes Research, United BioSource Corporation, Bethesda, MD, Kate Van Brunt, Center for Health Outcomes Research, United BioSource Corporation, London, UK, Donald L. Patrick, Public Health, University of Washington, Seattle, WA

### 143/1078/The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for patients with Endometrial Cancer: EORTC QLQ-EN24

Susanne Singer, Medical Psychology and Medical Sociology, University of Leipzig, Leipzig, Germany, Elfriede Greimel, Obstetrics and Gynecology, Medical University of Graz, Graz, Austria, on behalf of the EORTC Quality of Life Group, Gyn. Modules, EORTC, Brussels, Belgium

### 144/1233/Implementation of Quality of Life Evaluation in Oncology daily practice: Validation of EORTC-QLQ C30 and EORTC- H&N 35 Portuguese PC-software version.

Augusta A. Silveira, Health Sciences, Fernando Pessoa University, Porto, Portugal, Maria Teresa D. Sequeira, Health Sciences, Fernando Pessoa University; IBMC, Porto, Porto, Cláudia P. Ribeiro, Health Sciences, Portuguese Catolic University, Porto, Portugal, Joaquim J. Gonçalves, Informatics, IPCA, Famalicão, Portugal, Maria Isabel D. Sequeira, Oncology, Portuguese Oncology Institute, Porto, Portugal, Monteiro Eurico, Health Sciences, Fernando Pessoa University, Porto, Portugal, Carlos Lopes, Biomedical Sciences, ICBAS, Porto, Portugal, Pimentel L. Francisco, Health Sciences, Aveiro University, Aveiro, Portugal

### 145/1456/Can a prophylactic percutaneous endoscopic gastrostomy for enteral nutrition prevent malnutrition and improve health related quality of life in head and neck cancer patients? A randomized study

Ewa Silander, Eva Hammerlid, Dept of Otolaryngology Head and Neck Surgery, Sahlgrenska University Hospital, Gothenburg, Sweden

### 146/1547/Development of a computer-adaptive version of the EORTC QLQ-C30 Fatigue Scale

Johannes M. Giesinger, Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Tyrol, Austria, Mogens Groenvold, Morten A. Petersen, Palliative Medicine, Bispebjerg Hospital, Copenhagen, x, Denmark, Eva-Maria Gamper, Georg Kemmler, Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, x, Austria, Teresa Young, Lynda Jackson MacMillan Centre, Mount Vernon Hospital, Middlesex, x, UK, Juan I. Arraras, Radiotherapeutic Oncology, Hospital of Navarre, Pamplona, x, Spain, Thierry Conroy, Medical Oncology, Centre Alexis Vautrin, Vandoeuvre-lès-Nancy, x, France, Tim Luckett, Madeleine T. King, School of Psychology, University of Sydney, Sydney, x, Australia, Irma M. Verdonck-de Leeuw, Otolaryngology Head and Neck Surgery, VU University Medical Cente, Amsterdam, x, The Netherlands, Bernhard Holzner, Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Tyrol, Austria

147/1194/Six-month postoperative quality of life predicts long-term survival after esophageal cancer surgery Therese Djärv, Inst of Mol Med and Surg, Pernilla Lagergren, Molecular Med and Surg, Karolinska Institutet, Stockholm, Sweden

### 148/1184/Development of computerized adaptive testing (CAT) for the EORTC QLQ-C30 physical functioning dimension

Morten A. Petersen, Dept. Palliative Medicine, Bispbjerg Hospital, Copenhagen, Denmark, Mogens Groenvold, Dept. Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark, Neil K. Aaronson, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands, Wei-Chu Chie, Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan, Thierry Conroy, Medical Oncology Department, Centre Alexis Vautrin, Vandruvre-les-Nancy, France, Anna Costantini, Psychoncology Unit, Sant'Andrea Hospital, 2nd Faculty of Medicine Sapienza University of Rome, Rome, Italy, Peter Fayers, Department of Public Health, University of Aberdeen, Aberdeen, UK, Jorunn Helbostad, Department of Neuroscience, St. Olav University Hospital, Trondheim, Norway, Bernhard Holzner, Department of psychiatry and psychotherapy, Medical University Innsbruck, Innsbruck, Austria, Stein Kaasa, Palliative Medicine Unit, St. Olav University Hospital, Trondheim, Norway, Susanne Singer, Department Medical Psychology and Medical Sociology, University of Leipzig, Germany, Galina Velikova, Cancer Research UK Centre, University of Leeds, Leeds, UK, Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middx, UK

### 149/1680/The Use of Patient-Reported Outcome Measures (PROMs) For People with the Four Most Common Cancers in the UK: A Structured Review

Monica Hadi, Carolina Casañas i Comabella, Elizabeth Gibbons, Anne Mackintosh, Ray Fitzpatrick, Public Health, University of Oxford, O

### 150/1291/Prognostic significance of patient heterogeneity in a dataset of 10,108 cancer patients.

Chantal Quinten, Francesca Martinelli, John Maringwa, Corneel Coens, Quality of Life Department, EORTC, Brussels, Belgium, Bryce Reeve, Division of Cancer Control & Population Studies, National Cancer Institute, NIH, Bethesda, MD, Caroline Gotay, Primary Prevention School of Population, University of British Columbia, Vancouver, British Columbia, Canada, Henning Flechtner, Medical Faculty, Otto-von-Guericke University Magdeburg, Magdeburg, Germany, Jolie Ringash, The Princess Margaret Hospital, University of Toronto, Toronto, Ontario, Canada, Eva Greimel, Obstetrics and Gynecology, Medical University Graz, Graz, Austria, Madeleine King, Psycho-oncology Co-operative Research Group, University of Sydney, Sydney, Australia, David Osoba, Quality of Life Consulting, Vancouver, British Columbia, Canada, Martin J. Taphoorn, Neurology, VU Medical Center/MC Haaglanden, The Hague, The Netherlands, Charles Cleeland, Symptom Research, University of Texas, Houston, Texas, Joachim Weis, Psychooncology, University of Freiburg, Freiburg, Germany, Joseph Schmucker-Von Koch, Philosophical Faculty, University of Regensburg, Regensburg, Germany, Andrew Bottomley, Quality of Life Department, EORTC, Brussels, Belgium

### 151/1535/Randomized trial of adjuvant chemotherapy with gemcitabine plus cisplatine versus docetaxel plus cisplatine in patients with completely resected non small cell lung cancer: quality of life, efficacy, and safety

Anderson Loundou, Marie-Claude Simeoni, Department Public Health, University Hospital, Marseille, France, Fabrice Barlesi, Department Pneumology, CHU Sainte Marguerite, Marseille, France, Cecile Fortanier, Karine Baumstarck-Barrau, Julie Berbis, Department Public Health, University Hospital, Marseille, France, Cristos Chouaid, Department Pneumology, CHU Saint Antoine, Paris, France, Herve Lecaer, Department Pneumology, CHG Draguignan, Draguignan, France, Alain Vergnenegre, Department Pneumology, CHU Limoges, Limoges, France, Pascal Auquier, Department Public Health, University Hospital, Marseille, France

### 152/1626/Self-reported quality of life independent of tumour location and tumour stage - no change in quality of life over time in melanoma patients

Sandra Nolte, Association of Dermatological Prevention (ADP e.V.), c/o Center of Dermatology Buxtehude, Buxtehude, Germany, A Waldmann, Institute of Cancer Epidemiology, University of Luebeck, Luebeck, Germany, E W. Breitbart, Center of Dermatology, Elbekliniken Buxtehude, Buxtehude, Germany, A Katalinic, Institute of Cancer Epidemiology, University of Luebeck, Luebeck, Germany

### 153/1373/Development of computer-adaptive testing (CAT): Building new systems or transforming existing instruments? An analysis of the consequences of the EORTC CAT strategy

Mogens Groenvold, Morten A. Petersen, Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark, Neil K. Aaronson, Division of Psychosocial Research & Epidemiology, Netherlands Cancer Institute, Amsterdam, Netherlands, Wei-Chu Chie, Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan, Thierry Conroy, Medical Oncology, Centre Alexis Vautrin, Vandeuvre-les-Nancy, France, Anna Costantini, Psychoncology Unit, Sant'Andrea Hospital, 2nd Faculty of Medicine Sapienza University of Rome, Rome, Italy, Peter M. Fayers, Public Health, University of Aberdeen, Aberdeen, UK, Johannes Giesinger, Psychiatry and Psychotherapy, University of Innsbruck, Innsbruck, Austria, Jorunn Helbostad, Neuroscience, St. Olav University Hospital, Trondheim, Norway, Bernhard Holzner, Psychiatry and Psychotherapy, Medical University Innsbruck, Innsbruck, Austria, Stein Kaasa, Palliative Medicine, St. Olav University Hospital, Trondheim, Norway, Susanne Singer, Medical Psychology and Medical Sociology, University of Leipzig, Leipzig, Germany, Galina Velikova, Cancer Research UK Centre, University of Leeds, Leeds, UK, Irma M. Verdonck-de Leeuw, Clinical Psychology, VU University, Amsterdam, Netherlands, Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Hospital, Northwood, UK

#### 154/1363/Creating consistency in translations: Case study of three Slavic languages

Dagmara Kulis, Petra Smith Jeglikova, Quality of Life, EORTC, Brussels, Belgium, Elfriede Greimel, Obstetrics and Gynecology, University of Graz, School of Medicine, Graz, Austria, Andrew Bottomley, Quality of Life, EORTC, Brussels, Belgium, Michael Koller, Center for Clinical Studies, University Hospital Regensburg, Regensburg, Germany

### 155/1140/Development of the Japanese version of the HRQOL instrument for patients with bone metastases: EORTC QLQ-BM22

Kojiro Shimozuma, Life Sciences, Ritsumeikan University, Kusatsu, Shiga, Japan, Takefumi Satoh, Urology, Kitasato University, Sagamihara, Kanagawa, Japan, Kunihiko Kobayashi, Respiratory Medicine, Saitama Medical University Int'l Medical Center, Hidaka, Saitama, Japan, Taisuke Hori, Palliative Care, Shiga Medical Center for Adults, Moriyama, Shiga, Japan, Shinsuke Iida, Medical Oncology & Immunology, Nagoya City University, Nagoya, Aichi, Japan, Atsushi Sato, Clinical Oncology, Showa University Hospital, Tokyo, Tokyo, Japan, Hiroshi Ishiguro, Outpatient Oncology Unit, Kyoto University Hospital, Kyoto, Kyoto, Japan, Takeru Shiroiwa, Life Sciences, Ritsumeikan University, Kusatsu, Shiga, Japan, Shinya Saito, Nursing, Okayama University, Okayama, Okayama, Japan, Edward Chow, Radiation Oncology, Sunnybrook Health Science Center, Toronto, Ontario, Canada

156/1584/Longitudinal analysis of quality of life in oncology using generalisations of the mixed Rasch model Julie Lorent, Sophie Gourgou-Bourgade, Biostatistics Unit, Val d'Aurelle Cancer center, Montpellier, France, Andrew Kramar, Biostatistics unit, Oscar Lambret Cancer center, Lille, France, Caroline Bascoul-Mollevi, Biostatistics unit, Val d'Aurelle cancer center, Montpellier, France

### 157/1654/Quality of life scores as possible stratification factors in clinical trials of mesothelioma: An analysis from the MRC MS01 trial

Matthew G. Nankivell, Clinical Trials Unit, Medical Research Council, London, UK, Martin F. Muers, Oncology, Leeds General Infirmary, Leeds, UK, Mahesh K. Parmar, Clinical Trials Unit, Medical Research Council, London, UK, Patricia Fisher, Oncology, Weston Park Hospital, Sheffield, UK, Richard J. Stephens, Clinical Trials Unit, Medical Research Council, London, UK

### 158/1371/Feasibility of quality of life measurement among cancer patients treated with palliative pelvic radiation: A pilot-study

Gudrun Rohde, Health and Sport, University of Agder, Kristiansand, Norway, Marte G. Cameron, Rene van Helvoirt, Center for Cancer Treatment, Ingvild Vistad, Gynecology, Christian Kersten, Center for Cancer Treatment, Sørlandet Hospital, Kristiansand, Norway

### 159/1623/Cross cultural study on the level of information received by cancer patients, through the EORTC information module.

Juan Ignacio Arraras, Medical and Radiotherapeutic Oncology, Hospital de Navarra, Pamplona, Navarra, Spain, Eva Greimel, Department of Obstetrics and Gynaecology, Medical University of Graz, Graz, Austria, Orhan Sezer, Hematology and Oncology, University Hospital Hamburg, Hamburg, Germany, Wei-Chu Chie, Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan, Mia Bergenmar, Department of Oncology, Karolinska Institutet Hospital Dep OncologyPathology, Stockholm, Sweden, Anna Constantini, Psychooncology Unit,, Sant'Andrea Hospital, Sapienza University of Rome, Rome, Italy, Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Cancer Centre, Northwood, Middlesex, U.K., Karin Kuljanic Vlasic, Gynaecology and Obstetrics, Clinical Hospital Center Rijeka, Rijeka, Croatia, Galina Velikova, University of Leeds, St Jamess Institute of Oncology, Leeds, U.K., Wei-Chu PhD, Graduate Institute of Preventive Medicine, College of Public Health, National Taiwan University, Taipei, Taiwan

#### 160/1327/Validation of Neuro-QOL Measures for People Diagnosed with Epilepsy

David Victorson, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Jose Cavazos, Neurology, University of Texas Health Science Center - San Anto, David Cella, Cindy Nowinski, Katy Wortman, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Claudia Moy, Extramural Research, NIH/NINDS

### 161/1308/Targeted Assessment for Individuals with Spinal Cord Injury: Extending the Neuro-QOL and PROMIS Measurement Systems

David Victorson, Medical Social Sciences, Northwestern University Feinberg School of Medicine, David Tulsky, Pamel Kisala, Spinal Cord Injury Research Laboratory, Kessler Foundation Research Center, David Cella, Medical Social Sciences, Northwestern University Feinberg School of Medicine

#### 162/1325/Validation of Neuro-QOL Measures for People Diagnosed with Multiple Sclerosis

Deborah Miller, Neurology, The Cleveland Clinic Foundation, Francois Bethoux, Neurology, The Cleveland Clinic, Cindy Nowinski, David Victorson, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Claudia Moy, Extramural Research, NIH/NINDS, Katy Wortman, David Cella, Medical Social Sciences, Northwestern University Feinberg School of Medicine

#### 163/1306/Quantifying our Progress: Calibration and Validation Testing of the Neuro-QOL Tool

Cindy Nowinski, David Cella, Jin Shei Lai, Medical Social Sciences, Northwestern University Feinberg School of Medicine

#### 164/1326/Clinical Validation of Neuro-QOL Measurement Tools in Parkinson's Disease

Cindy Nowinski, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Andrew Siderowf, Neurology, University of Pennsylvania Health System, David Victorson, David Cella, Katy Wortman, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Claudia Moy, Extramural Research, NIH/NINDS

#### 165/1693/Extending the Neuro-QOL to Huntington's Disease (HD): The development of the HD-HRQOL

Noelle E. Carlozzi, Heather McGowan, David S. Tulsky, Outcomes & Assessment Laboratory, Kessler Foundation Research Center, West Orange, NJ

#### 166/1170/Progress on the PROMIS® Sexual Function Measure

Kathryn E. Flynn, Psychiatry and Behavioral Sciences, Duke University School of Medicine, Durham, NC, Diana D. Jeffery, Center for Health Care Management Studies, Health Pr, US Department of Defense, Bryce B. Reeve, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, L Lin, Duke Clinical Research Institute, Durham, NC, Ashley Wilder Smith, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, A Abernethy, Duke Clinical Research Institute, Durham, NC, J Reese, Johns Hopkins University, Baltimore, MD, Kevin Weinfurt, Dept. of Psychology & Neuroscience, Duke University

### 167/1768/The NIH Patient-Reported Outcomes Measurement Information System Cancer Fatigue Item Bank (PROMIS Ca-FIB): Validation with Cancer Population

Jin-Shei Lai, Sofia F. Garcia, David Cella, Medical Social Sciences, Northwestern University, Chicago, IL

#### 168/1328/Development of Targeted Patient Reported Outcome Item banks for Spinal Cord Injury: The SCI-CAT/ SCI-QOL Measurement System

David Tulsky, Spinal Cord Injury Research Laboratory, Kessler Foundation Research Center, Summit, NJ, Alan M. Jette, Health & Disability Research Institute, Boston University School of Public Health, Allen W. Heinemann, Center for Rehabilitation Outcomes Research, Rehabilitation Institute of Chicago, Denise G. Tate, Department of Physical Medicine and Rehabilitation, University of Michigan Medical School, David Cella, Deaprtment of Medical Sciences, Northwestern University Feinberg School of Medicine

#### 169/1717/Development of a Vision-Targeted HRQOL Item Bank

Sylvia H. Paz, Health Services, UCLA, La Canada, CA, Jerry Slotkin, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, Roberta McKean-Cowdin, Preventive Medicine, Rohit Varma, Ophthalmology, University of Southern California, Los Angeles, CA, Ron D. Hays, Medicine, UCLA, Los Angeles, CA

### 170/1788/Comparing health status profiles administered to common samples when their range, variability and available norms vary

Seung W. Choi, Jennifer L. Beaumont, Medical Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL, Zhimei Liu, US Oncology Health Economics & Outcomes Research, Novartis Pharmaceuticals Corporation, East Hanover, NJ, James C. Yao, Gastrointestinal Medical Oncology, University of Texas M. D. Anderson Cancer Center, Houson, TX, David Cella, Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL

#### 171/1429/Acceptance and Usability of Assessment Center

Nan Rothrock, Rachel Hanrahan, Richard Gershon, Medical Social Sciences, Northwestern University, Chicago, IL

### 172/1742/Agreement Between PROMIS Global Health Scale and SF-36 Scores Among Surgical Patients

David R. Nerenz, Center for Health Services Research, Lisa Pietrantoni, Neuroscience Institute, Lonni Schultz, Biostatistics and Research Epidemiology, Leila Obeid, Andrew Swartz, Surgery, Ilan Rubinfeld, Trauma Surgery, Vic Velanovich, Surgery, Henry Ford Hospital, Detroit, MI

### **Population & Policy**

### 173/1664/Assessment of quality of life of family and their willingness to trade off pay and time for symptom free patients with skin disease

Mohammad Basra, Rhiannon McKnight, Dermatology, Sam Salek, Pharmacy, Cardiff University, Cardiff, UK

#### 174/1114/Quality of Life and Burden in Caregivers of Elderly in Outpatient Treatment

Déborah C. Oliveira, Gisele S. F. Carvalho, Faculty of Medical Sciences - Nursing Department, Florindo Stella, Celina M. H. Higa, Ambulatory of Mental Health, Maria J. D'Elboux, Faculty of Medical Sciences - Nursing Department, State University of Campinas, Campinas, São Paulo, Brazil

### 175/1627/Age and Ethnic Variations in Caregiver Burden, Self-Efficacy, and Quality of Life among Working Caregivers

Joan J. Branin, Center for Health & Aging, University of La Verne, La Verne, CA

#### 176/1601/The secondary impact of skin disease on the Greater Patient

Andrew Y. Finlay, Dermatology, Cardiff University, UK

### 177/1270/Health-related quality of life and depressive symptoms in mothers of children and adolescents with myelomeningocele

Danielle M. Morais, Health Sciences, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil, Carlos H. Rezende, Internal Medicine, Helena B. Paro, Health Sciences, Federal University of Uberlandia, Uberlândia, Minas Gerais, Brazil, Eliane M. Santos, Health Sciences, Nívea M. Morales, Neurology, Carlos H. Silva, Pediatrics, Rogério M. Pinto, Mathematics, Federal University of Uberlândia, Uberlândia, Minas Gerais, Brazil

### 178/1671/Psoriasis Family Index (PFI-15): Validation of a Disease Specific Quality of Life Tool for Family Members of Psoriasis Patients

Mohammad Basra, Dermatology, Sam Salek, Mari Fairfax, Pharmacy, Cardiff University, Cardiff, UK

#### 179/1720/Family's quality life for children with Spinal Muscular Atrophy

Mirna A. Frota, NURSING, INGRID M. ALVES, PHYSIOTHERAPY, VANESSA G. SILVEIRA, NUTRICION, CAROLINE S. NOBRE, LUIZA LUANA A. LIRA, CINTIA F. CASIMIRO, NURSING, UNIVERSITY OF FORTALEZA, FORTALEZA, CEARA, BRAZIL

### 180/1174/Extended vs. Sextant Prostate Biopsy: A Cost-Effectiveness Analysis Supporting Acceptance of Extended Biopsy Schemes as Standard of Care

Jeffrey S. Montgomery, Yun Zhang, Ted A. Skolarus, Brent K. Hollenbeck, John T. Wei, Urology, University of Michigan, Ann Arbor, Michigan

#### 181/1741/Multinational Evaluation of Conditional Median Models of EQ-5D Health State Preferences

James W. Shaw, Lin Zhan, Pharmacy Administration, University of Illinois at Chicago, Chicago, IL, Mark Oppe, Institute for Medical Technology Assessment, Erasmus University Rotterdam, Rotterdam, The Netherlands, A. Simon Pickard, Pharmacy Practice, University of Illinois at Chicago, Chicago, IL

#### 182/1495/Efficiency of Statistical Analyses of the US Population Median-Based EQ-5D Index

James W. Shaw, Xiaochen Luo, Surrey M. Walton, Pharmacy Administration, A. Simon Pickard, Pharmacy Practice, University of Illinois at Chicago, Chicago, IL

#### 183/1043/Race Differences in Preference-based Health-related Quality of Life in the United States

Claudia C. Pereira, Population Family and Reproductive Health, Johns Hopkins University, Baltimore, MD, Mari Palta, John Mullahy, Population Health Sciences, University of Wisconsin - Madison, Malison, WI

### 184/1310/Population Health Status of 5354 South Asians and African-Caribbeans in the United Kingdom: Implications for Health Policy

Melanie J. Calvert, Nick Freemantle, Helen Duffy, School of Health & Population Science, Russell Davis, Centre for Cardiovascular Science, University of Birmingham, Birmingham, UK, Michael Davies, Cardiology, University Hospitals Birmingham NHS Trust, Birmingham, UK, Gregory Lip, Centre for Cardiovascular Science, Paramjit Gill, School of Health & Population Science, University of Birmingham, Birmingham, UK

#### 185/1386/Psychometric comparison of EQ-5D and EQ-5D-5L in student population

Dominik Golicki, Szymon Zawodnik, Pharmacoeconomics, Medical University of Warsaw, Warsaw, Poland, Mathieu F. Janssen, EuroQol Group, Rotterdam, The Netherlands, Aleksandra Kiljan, Tomasz Hermanowski, Pharmacoeconomics, Medical University of Warsaw, Warsaw, Poland

### 186/1399/Health status preferences and population norms for the SF-6D

Pedro L. Ferreira, Centre for Health Studies & Research, Faculty of Economics, University of Coimbra, Coimbra, Portugal, Lara N. Ferreira, Centre for Health Studies & Research, ESGHT-University of the Algarve, Faro, Portugal

#### 187/1783/Calibration of Quality-Adjusted Life Years (QALYs) for Oncology Clinical Trials (OCT)

Jeff A. Sloan, Paul J. Novotny, Daniel J. Sargent, Paul Decker, Health Sciences Research, Mayo Clinic, Rochester, MN

### 188/1283/Is Health Preference Derived from the SF-36v2 Equivalent to that Measured by the SF-6D Health Survey?

Cindy L. Lam, Carlos K. Wong, Elegance T. Lam, Family Medicine Unit, the University of Hong Kong, Hong Kong SAR, China

### 189/1252/Confirmatory Factor Analysis of the Domains from Four Health-Related Quality of Life Preference Measures

Gregory A. Maglinte, Health Services, UCLA, Woodland Hills, CA, Ron D. Hays, Medicine, Robert M. Kaplan, Health Services, UCLA, Los Angeles, CA

#### 190/1659/Multinational Evaluation of Conditional Median Models of EQ-5D Health State Preferences

Lin Zhan, College of Pharmacy, UIC, Dalian, Liao Ning Province, China, James W. Shaw, College of Pharmacy, UIC, chicago, IL

### 191/1477/Cross-cultural adaptation of the KIDSCREEN-52 questionnaire to measure quality of life in a national sample of Chilean adolescents

Diego J. Salazar, Public Health, Rodrigo F. Sepúlveda, Faculty of Medicine, Electra V. González, Adela R. Montero, Temístocles E. Molina, Vania A. Martínez, CEMERA, Faculty of Medicine, Myriam L. George, Psychology, Rosa E. Montaño, Public Health, University of Chile, Santiago, Chile, Carlos A. Hidalgo Rasmussen, Culture Arts and Humanities, University of Guadalajara, Guadalajara, Jalisco, México, Ramiro E. Molina, CEMERA, Faculty of Medicine, University of Chile, Santiago, Chile

#### 192/1631/Validation of the KIDSCREEN-52 Instrument for Chilean School Teenagers Population

Ramiro C. Molina, DIEGO SALAZAR, RODRIGO SEPULVEDA, ELECTRA A. GONZALEZ, ROSA MONTAÑO, TEMISTOCLES MOLINA, ADELA MONTERO, VANIA N. MARTINEZ, MYRIAM GEORGE, Carlos Hildalgo, MEDICINA, UNIVERSIDAD DE CHILE, SANTIAGO, CHILE

### 193/1300/CHQ-PF28 Profile in 13-year-old Polish Adolescents in Relation to Family Socioeconomic Status in the First Year of Their Life

Joanna Mazur, Agnieszka Malkowska-Szkutnik, Child and Adolescent Health, Institute of Mother and Child, Warsaw, Poland

194/1380/Is health related quality of life among school children associated with level of semantic memory? Eva Boman, Peter Bällgren, Department of Social Work and Psychology, University of Gävle, Gävle, Sweden, Pia Svedberg, Division of Insurance Medicine, CNS, Karolinska Institutet, Stockholm, Sweden

#### 195/1166/Valuing social and conduct disorders in children and adolescents; results from expert panels

Karin M. Vermeulen, Epidemiology, University Medical Center Groningen, Groningen, Groningen, The Netherlands, Danielle E. Jansen, Annemieke H. Luinge, Health Sciences-Public Health, University of Groningen, Groningen, Groningen, The Netherlands, Erik Buskens, Epidemiology, University Medical Center Groningen, Groningen, Groningen, The Netherlands, Erik J. Knorth, Special Needs Education and Youth Care, Sijmen A. Reijneveld, Health Sciences-Public Health, University of Groningen, Groningen, Groningen, The Netherlands

#### 196/1770/Physical Activity, Sedentary Behavior and Quality of Life in Ethnically Diverse U.S. Youth

Anne M. Skalicky, Todd C. Edwards, Alan Kuniyuki, Health Services, University of Washington, Seattle, WA, Leo S. Morales, Group Health Research Institute, Group Health Cooperative, Seattle, WA, Yvonne Flores, Health Services, University of California, Los Angeles, Los Angeles, CA, Donald L. Patrick, Health Services, University of Washington, Seattle, WA

#### 197/1276/New Card System Quality of Life (QOL) Questionnaire for Infant

Rika Hayashida, University of Nagasaki, Siebold, Nishisonogi-gun, NAGASAKI, Japan, Kanae Yanagisako, The Jikeikai University Hospital, Minatoku, Tokyo, JAPAN, Michiko Kobayashi, Kwassui Women's College, Omura, NAGASAKI, JAPAN, Takashi Mandai, (National Cerebral and Cardiovascular Center),, Japanese Society of Quality of Life Research, Sumaku, Kobe, Hyogo, JAPAN

### 198/1697/Relation Between Functionality and HRQOL of Patients with Juvenile Idiophatic Arthritis According to Age Group

Tania Maria S. Mendonça, Physioterapy, Universidade Federal de Uberlândia, Uberlândia, Minas Gerais, Brazil, Len A. Cláudio, hilario E. Maria Odete, Pediatrics, Universidade Federal de São Paulo, São Paulo, São Paulo, Brazil, Silva M. Carlos Henrique, Pediatrics, Rogério M. Costa Pinto, Mathematics, Universidade Federal de Uberlândia, Uberlândia, Minas Gerais, Brazil

### 199/1699/Postnatal Quality of life and Mental Health in Normal and Caesarean Delivery

Aggeliki Leonardou, Maria Ginieri-Coccossis, George Papadimitriou, Ioannis Zervas, Psychiatry, University of Athens, Greece, Athens, Attiki, Greece

### 200/1746/Psychometric proprieties of the Youth Quality of Life Instrument-Research (YQOL-R) Brazilian version

Giovanni A. Salum, Gisele G. Manfro, Post-graduate Program in Medical Sciences/Psychiatry, Universidade Federal do Rio Grande do Sul, Porto Alegre, RS, Brazil, Marcelo P. Fleck, Psychiatry, Universidade Federal do Rio Grande do Sul, Porto Alegre, Rio Grande do Sul, Brazil

### 201/1388/Quality of life of youth who were born premature or with a congenital heart defect: How do they measure up?

Noémi Dahan-Oliel, Annette Majnemer, Barbara Mazer, Rehabilitation Science, McGill University, Montreal, Quebec, Canada

### 202/1415/Health-related quality of life(HRQOL) measurement in children and adolescents in Iberoamerican countries, 2000-2010

Luis Rajmil, URSS, Municipal Institute of Medical research, Barcelona, Spain, Mariana Roizen, Commite of Quality of life Bone Marrow Transplant, Hospital Garrahan, Buenos Aires, Argentine, Alfonso Urzúa, Psychology, Universidad Católica del Norte, Antofagasta, Chile

### 203/1428/Adaptation and Validation of the Pediatric Quality of Life Inventory PedsQL 4.0 - Generic Core Scales to the Portuguese culture

Joao N. Gil, Pedro L. Ferreira, CEISUC, Coimbra, Portugal, Carla F. Baltazar, Lisboa, Portugal, Cavalheiro N. Luis, CEISUC, Coimbra, Portugal, Jan Cabri, Physical Performance, Norwegian School of Sport Science, Oslo, Norway

### 204/1482/Evaluation of the content of quality of life instruments applied to children and adolescents with cerebral palsy, according to the International Classification of Functioning, Disability and Health(ICF)

Andressa A. Teymeny, Health Sciences, AACD-MG and Federal University Of Uberlandia, Uberlandia, Minas Gerais, Brazil, Nívea M. Morales, Neurology, Federal University Of Uberlandia, Uberlandia, MG, Brazil, Elidiane M. Soares, medical, Federal University Of Uberlandia, Uberlandia, Uberlandia, MG, Uberlandia, Rogério M. Pinto, Mathematics, Carlos H. Rezende, Medical Clinics, Helena M. Paro, Health Sciences, Federal University Of Uberlandia, Uberlandia, MG, Brazil, Rogério R. Morales, Neurology, Federal University Of Uberlandia, MG, Brazil, Carlos H. Silva, Pediatrics, Federal University Of Uberlandia, Uberlandia, MG, Brazil

### 205/1532/Determinants of agreement between self-reported and parent-assessed quality of life for children in Germany

Ute Ellert, Epidemiology and Health Reporting, Robert Koch Institute, Berlin, Germany, Ulrike Ravens-Sieberer, Michael Erhart,

Psychosomatics in Children and Adolescents, University Medical Centre Hamburg-Eppendorf, Hamburg, Germany, Bärbel-Maria Kurth, Epidemiology and Health Reporting, Robert Koch Institute, Berlin, Germany

#### 206/1555/Quality of Life of Children Born Preterm at School-Age

Julie Berbis, Department Public Health, University Hospital, Marseille, France, Marie-Ange Einaudi, Paediatrics, Marie-Claude Simeoni, Public Health, Véronique Brévaut-Malaty, Paediatrics, Claude d'Ercole, Obstetrics and Gynaecology, Catherine Gire, Paediatrics, Nord University Hospital, Marseille, France

#### 207/1609/T-QoI: a novel dermatology-specific measure for adolescents with skin diseases Sam Salek, Pharmacy, Cardiff University, UK

208/1362/Health Related Quality of life in children and adolescents: Reliability and validity of the Norwegian version of KIDSCREEN-52 questionnaire, a cross sectional study.

Kristin Haraldstad, Department of Nursing Research, Oslo University College,, N-0167 Oslo, Norway, Knut A. Christophersen, Institute of Political Science, University of Oslo, 0317 Oslo,, Norway, Solvi Helseth, Department of Nursing Research, Hilde Eide, Dep of Nursing research, Oslo University College, N-0167 Oslo, Norway, Gerd karin Natvig, Department of Public Health and Primary Care, University of Bergen, Bergen, Norway

Poster Session 3 Saturday, October 30 Viscount Suite and Foyer

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#### **Clinical Practice & Research**

### 209/1239/Perceived communication between patients and healthcare providers as a determinant of health-related quality of life in breast cancer patients: longitudinal approach

Julie G. Trudel, Nicole LEDUC, École de santé publique, Université de Montréal, Montréal, Québec, CANADA, Serge DUMONT, École de service social, Université Laval, Québec, Québec, CANADA

### 210/1450/Evolution of the association between perceived communication and health-related quality of life among breast cancer patients in relation to clinical, intrapersonal and interpersonal factors

Julie G. Trudel, Nicole LEDUC, École de santé publique, Université de Montréal, Montréal, Québec, CANADA, Serge DUMONT, École de service social, Université Laval, Québec, Québec, CANADA

### 211/1553/Perceived quality of life in Portuguese women with breast cancer and their partners. Presentation of an explanatory mode

Maria J. Cunha, João P. Pereira, Andreia D. Sousa, Psychology, Instituto Superior da Maia, Avioso S. Pedro, Portugal, Pedro Lopes, Medicine, Faculdade de Medicina da Universidade de Coimbra, Coimbra, Portugal, Cecilia Loureiro, Ludovina Azevedo, Psychology, Instituto Superior da Maia, Avioso S. Pedro, Portugal

### 212/1648/Development of a new BREAST-Q module for Breast Cancer Patients: The Breast-Conserving Therapy (BCT) Module

Amie M. Scott, Colleen M. McCarthy, Surgery, Memorial Sloan-Kettering Cancer Center, New York, NY, Anne F. Klassen, Pediatrics, McMaster University, Hamilton, ON, Canada, Stefan J. Cano, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, UK, Andrea L. Pusic, Surgery, Sabrina M. Jhanwar, Psychiatry and Behavioral Sciences, Monica Morrow, Surgery, Memorial Sloan-Kettering Cancer Center, New York, NY

### 213/1376/Outcomes and Costs of Nanoparticle Albumin-Bound(nab-) Paclitaxel Compared to Docetaxel in Women with Pretreated Metastatic Breast Cancer.

Christina M. Donatti, Health Economics & Outcomes Research, IMS Health, London, UK, Euan McLeod, Adam Lloyd, Health Economics & Outcomes Research, IMS Health, London, United Kingdom, François J. Prunièras, Pricing and Reimbursement, Abraxis Bioscience, Paris, France

## 214/1009/Study on the Quality of Life & Determinants for Patients Undergoing Lithotripsy for Urinary Stones Mostafa A. Arafa, Princess Al Johara Al Ibrahim for cancer research, Danny M. Rabah, Urolgy, King Saud University, Rlyadh, saudi Arabia

#### 215/1221/Quality of Life after cholecystectomy: results of a prospective study

Marlies Mertens, Medical Psychology and Neuropsychology, Tilburg University, Tilburg, The Netherlands, Jan A. Roukema, Surgery, St. Elisabeth Hospital, Tilburg, the Netherlands, Jolanda de Vries, Medical Psychology and Neuropsychology, Tilburg University, Tilburg, the Netherlands

#### 216/1318/HRQOL and Side effects on Cessation of Medical Therapy for Benign Prostatic Hyperplasia (BPH)

Rodney L. Dunn, Urology, University of Michigan, Ann Arbor, Michigan, John T. Wei, Urology, University of Michigan, Ann Arbor, MI, Martin Miner, Family Medicine, Brown University, Providence, RI, David J. Pasta, Statistics & Data Operations, ICON Clinical Research, San Francisco, CA, Catherine A. Spino, Biostatistics, University of Michigan, Ann Arbor, MI, Claus Roehrborn, Urology, UT Southwestern Medical School, Dallas, TX, Raymond C. Rosen, Chief Scientist, New England Research Institutes, Waterton, Massacussetts, Allen D. Seftel, Urology, UH Case Medical Center, Cleveland, OH, Wendy J. Carman, Drug Safety, i3 Drug Safety, Ann Arbor, MI

### 217/1690/Application of Exploratory Factor Analysis to Support the Conceptual Framework of PRO Measures: Results from a Phase 2 Study of Irritable Bowel Syndrome with Constipation

Valerie Williams, Patient-Reported Outcomes, RTI Health Solutions, Research Triangle Park, NC, Robyn T. Carson, Health Economics & Outcomes Research, Forest Research Institute, Jersey City, NJ, Lauren M. Nelson, Patient-Reported Outcomes, RTI Health Solutions, Research Triangle Park, NC, James W. MacDougall, Biometrics, Ironwood Pharmaceuticals, Cambridge, MA, Sheri E. Fehnel, Patient-Reported Outcomes, RTI Health Solutions, Research Triangle Park, NC, Barbara E. Lewis, Health Economics and Outcomes Research, Jeffrey M. Johnston, Clinical, Biometric & Regulatory Affairs, Ironwood Pharmaceuticals, Cambridge, MA

### 218/1604/Conceptual definition of PRO measures: a case study with the Quality of Life in Inflammatory Bowel Disease Questionnaire(IBDQ)

Katrin Conway, MAPI Research Trust, Lyon, France, Isabelle Mear, MAPI Institute, Lyon, France, Catherine Acquadro, MAPI Research Trust, Lyon, France, Elizabeth Jan Irvine, Gastroenterology, St Michael's Hospital, Toronto, Ontario, Canada

#### 219/1331/Relative Impact of Urinary Conditions on Quality of Life

Aruna V. Sarma, Rodney L. Dunn, Urology, University of Michigan, Ann Arbor, MI, Martin Miner, Family Medicine, Brown University, Providence, RI, David J. Pasta, Statistics & Data Operations, ICON Clinical Research, San Francisco, CA, Claus Roehrborn,

Urology, UT Southwestern Medical School, Dallas, TX, Raymond C. Rosen, Chief Scientist, New England Research Institutes, Watertown, MA, Allen D. Seftel, Urology, UH Case Medical Center, Cleveland, OH, Catherine A. Spino, Biostatistics, John T. Wei, Urology, University of Michigan, Ann Arbor, MI, Wendy J. Carman, Drug Safety, i3 Drug Safety, Ann Arbor, MI

**220/1590/Abdominal symptoms in relation to perceived health in patients with familial adenomatous polyposis** *Kaisa Fritzell, Lars E. Eriksson, Neurobiology, care sciences and society, Karolinska Institute, Huddinge, Sweden, Jan Björk, Rolf Hultcrantz, Medicine, Karolinska Institute, Stockholm, Sweden, Lena Wettergren, Neurobiology, care sciences and society, Karolinska Institute, Huddinge, Sweden* 

#### 221/1592/Development of Patient Reported Outcomes (PROs) in Ulcerative Colitis and Crohn's Disease

Patricia A. Wren, Health Sciences, Oakland University, Rochester, MI, Carrie L. Bergmans, Peter D. Higgins, Gastroenterology, The University of Michigan, Ann Arbor, MI

### 222/1093/The Development of a Social Morbidity Score in Patients with Chronic Ulcerative Colitis as a Guide to Treatment

Jason J. Smith, Colorectal Surgery, West Middlesex Univ. Hospital / Imperial College, Isleworth, Middlesex, UK, R John Nicholls, Colorectal Surgery, St Mark's Hospital / Imperial College, Harrow, Middlesex, UK

### 223/1596/The development of the Ascites Impact Measure questionnaire to assess patient symptoms that trigger a paracentesis

Bruce Crawford, Elisabeth Piault, PRO, MAPI Values, Boston, MA, Hélène Corson, Oncology, Sanofi-Aventis R&D, Vitry-sur-Seine, France, Walter Gotlieb, Jewish General Hospital, McGill University, Montreal, Quebec, Canada

### 224/1616/Psychometric validation of the Ascites Impact Measure questionnaire to assess patient symptoms that trigger a paracentesis

Elisabeth Piault, Yating Yeh, Bruce Crawford, PRO, MAPI Values, BOSTON, MA, Florence Joulain, PVD, Sanofi-Aventis R&D, Massy, FRANCE, Walter Gotlieb, Jewish General Hospital, McGill University, MONTREAL, Quebec, Canada

### 225/1187/Relationship between changes in opioid induced constipation symptoms and patient satisfaction in response to prucalopride.

René Kerstens, Biometrics and Data Management, Movetis, Turnhout, Belgium, Luc Wouters, I-BioStat, Hasselt University, Diepenbeek, Belgium, Lieve Vandeplassche, Clinical Research, Movetis, Turnhout, Belgium, Dominique Dubois, Outcomes Research, Patient Value Solutions, Huldenberg, Belgium

#### 226/1545/Depression and Anxiety in Patients with Autoimmune Hepatitis

Inka Wahl, Psychosomatic Medicine and Psychotherapy, Christina Weiler-Norman, Christoph Schramm, Internal Medicine, Bernd Löwe, Matthias Rose, Psychosomatic Medicine and Psychotherapy, University Medical Center Hamburg-Eppendorf, Hamburg, Hamburg, Germany

### 227/1343/Clinical Validation of a Short Urinary Incontinence Measure and its Correlation with Measures of HRQOL

Jan Sansoni, Nick Marosszeky, Glenn Fleming, Centre for Health Service Development, University of Wollongong, Wollongong, NSW, Australia, Graeme Hawthorne, Psychiatry, University of Melbourne, Parkville, Victoria, Australia

### 228/1157/Validation of the International Classification of Functioning, Disability and Health (ICF) Core Sets on stroke-specific outcome measurement

Chia-Yeh Chou, Occupational Therapy, Fu Jen Catholic University, Sinjhuang city, Taipei County, Taiwan, R.O.C

#### 229/1307/Impact on Functioning and Quality of Life of Hemiplegia after Stroke

María G. Borelli, Rehabilitation and Physical Medicine, CASMU-IAMPP, Montevideo, Uruguay, Juan J. Dapueto, Medical Psychology, Facultad de Medicina, Universidad de la República, Montevideo, Uruguay, María M. Vázquez, Physical Medicine and Rehabilitation, Facultad de Medicina Universidad de la República, Montevideo, Uruguay, María L. Tutté, Physical Medicine and Rehabilitation, Facultad de Medicina, Universidad de la República, Montevideo, Uruguay, Ignacio R. Salamano, Statistics, National Administration of Public Education, Montevideo, Uruguay, María del Carmen Abreu, Medical Psychology, Facultad de Medicina, Universidad de la República, Montevideo, Uruguay

### 230/1341/Adaptive domestic activities improve quality of life (QOL)in chronic stroke patients

Yoko Goto, Mariko Nakamura, Occupational Therapy, School of Health Science, Sapporo Medical University, Sapporo, Japan, Yuko Sasaki, Health and Nutrition, Sendai Shirayuri Women's College, Sendai, Japan, Kayako Hamanaka, Kazuyuki Kobayashi, Technology development, Tokyo electric power Co., Yokohama, Japan

#### 231/1432/Reliability and validity of the Portuguese version of the Stroke Impact Scale 2.0

Rui S. Goncalves, Joao N. Gil, Luis Cavalheiro, CEISUC, Coimbra, Portugal, Rui D. Costa, College of Health, University of Aveiro, Aveiro, Portugal, Pedro L. Ferreira, CEISUC, Coimbra, Portugal

#### 232/1459/Sexual experience in disability - comparative study in Spinal Cord Injury and Stroke

Carla S. Vicente, Rui A. Oliveira, Psychology, University of Évora, Évora, Évora, Portugal

### 233/1506/Use of the LIFE-H in stroke rehabilitation: a structured review of its psychometric properties

Sabrina Figueiredo, Nicol Korner-Bitensky, School of Physical and Occupational Therapy, McGill University, Montreal, QC, Canada, Annie Rochette, School of Rehabilitation, Universite de Montreal, Montreal, QC, Canada, Johanne Desrosiers, School of Rehabilitation, Universite de Sherbrooke, Sherbrooke, QC, Canada

#### 234/1656/Development and Validation of a Model of Participation Post Stroke: A Mixed Methods Approach

Ruth Barclay-Goddard, Physical Therapy, School of Med Rehabilitation, Jacquie Ripat, Occupational Therapy, School of Med Rehabilitation, University of Manitoba, Winnipeg, Manitoba, Canada

### 235/1409/The Relationship Between Habitual Physical Activity and Exercise Capacity to Quality of Life in Stroke Patients in Primary Care.

Olive C. Lennon, Catherine Blake, Public Health, Physiotherapy and Population Science, University College Dublin, Dublin, Dublin, Ireland

#### 236/1778/Quality of life measurement in head neck cancer patients: systematic review

Hsueh-Erh Liu, Nursing, Chang Gung University, Tao-Yuan, Taiwan, ROC.

#### 237/1522/The Impact of Comorbidity to HRQOL in Nasopharyngeal Cancer Patients

Yu-Ching Chang, Radiation Oncology, Chang Gung Memorial Hospital, Taoyuan, Taiwan, Taiwan, Ching-Rong Lin, Nursing, Chang Gung University, Kwei-Shan, Taiwan, Joseph T. Chang, Radiation Oncology, Chang Gung University, Taoyuan, Taiwan, Taiwan, Chih-Hung Chang, Methodology and Infometrics Section, Northwestern University, Chicago, IL

### 238/1524/The Impact of Total Laryngectomy and Comorbidity to HRQOL in Laryngeal Cancer and Hypopharyngeal Cancer Patients

Hsin-Yi Kuan, Radiation Oncology, Chang Gung Memorial Hospital, Guishan Township, Taoyuan, Taiwan, Taiwan, Ching-Rong Lin, Nursing, Chang Gung University, Kwei-Shan, Taiwan, Taiwan, Chih-Hung Chang, Methodology and Infometrics Section, Northwestern University, Chicago, IL, Joseph T. Chang, Radiation Oncology, Chang Gung University, Kwei-Shan, Taiwan, Taiwan

### 239/1588/Implementation of a quality of life assessment into the routine of a Dermatological University Clinic. First experiences in a pilot study

Julia M. Steinbauer, Dermatology, University Hospital, Regensburg, Germany, Regensburg, Bavaria, Germany, Michael Koller, Center for Clinical Studies, Regensburg University Hospital, Regensburg, Regensburg, Bavaria, Germany

# 240/1193/Translation and linguistic validation of the FACT-M for use with melanoma patients across the globe Benjamin J. Arnold, Fortaleza, Ceará, Brazil, Lillian Savic, Jayeeta Dhar, Scott Debb, FACITtrans, Elmhurst, IL, Jennifer Beaumont, David Cella, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Chicago, IL

#### 241/1223/The Association of Pretreatment Quality of Life with Survival of Patients with Foregut Carcinoma Vic Velanovich, Surgery, Henry Ford Hospital, Detroit, Michigan

#### 242/1224/The Importace of Method in the Variation of Pain Measurement in Surgical Patients

Vic Velanovich, David Goodyear, Surgery, Henry Ford Hospital, Detroit, Michigan

### 243/1160/Is the combined WHOQOL-Brèf and Pain and Discomfort Module a valuable outcome measure to use in assessing chronic pain

Hanne Bruhn, Centre of Academic Primary Care, University of Aberdeen, Aberdeen City, UK, Paul McNamee, Health Ecomomics Research Unit, Christine M. Bond, Centre of Academic Primary Care, University of Aberdeen, Aberdeen, UK, Richard Holland, School of Medicine, Health Policy and Practice, University of East Anglia, Norwich, UK

#### 244/1153/Predictors of Function in Chronic Pain Patients

Thomas E. Elliott, Research, SMDC Health System, University of Minnesota Duluth, Duluth, Minnesota, Colleen M. Renier, Jeanette A. Palcher, Research, SMDC Health System, Duluth, Minnesota

#### 245/1436/Reliability and validity of Portuguese version of the Pain Impact Questionnaire

Luis Cavalheiro, Joao N. Gil, Rui S. Goncalves, CEISUC, Coimbra, Portugal, Paula Pacheco, College of Health Technology of Coimbra, Coimbra, Portugal, Pedro L. Ferreira, CEISUC, Coimbra, Portugal

### 246/1165/Quantifying the Patient-Reported Burden of Herpes Zoster and Post-Herpetic Neuralgia in the UK: Practical Considerations

Adam Gater, Bollington, Cheshire, UK, Stuart Carroll, Sanofi Pasteur MSD, Maidenhead, Berkshire, United Kingdom, Linda Abetz, Dirk Demuth, Fiona Smith, Bollington, Cheshire, United Kingdom, Azharul Mannan, Sanofi Pasteur MSD, Maidenhead, Berkshire, United Kingdom

### 247/1100/Clinical outcome of a multidisciplinary pain management program, focusing on occupational performance.

Kersti A. Samuelsson, Rehabilitation medicine, Ewa Wressle, Geriatric, University Hospital, Linköping, Sweden

### 248/1442/Chronic Pain Management: Impact on Spiritual Functioning and Quality of Life

Barbara A. Elliott, Family Medicine and Community Health, University of Minnesota School of Medicine, Duluth, MN, Thomas E. Elliott, Research, SMDC Health System, Duluth, MN

#### 249/1479/A world-wide-web study of patients with cardiac disease and continuing chest pain

Brian Tiplady, PRO Consulting, Edinburgh, UK

#### **Methods & Methodology**

### 250/1481/A qualitative interview study of patients with cardiac disease and continuing chest pain Brian Tiplady, PRO Consulting, Edinburgh, UK

251/1231/Assessing and demonstrating data saturation in qualitative patient-reported outcomes (PRO) research Cicely Kerr, Patient Report Outcomes, Annabel Nixon, Diane Wild, Patient Reported Outcomes, Oxford Outcomes, Oxford, UK

### 252/1203/Responsiveness and Minimally Important Difference of the 10-Item MOA Quality of Life Questionnaire (MQL-10): Results from a 12-Week Follow-up Survey on Complementary Health Practices

Tomoaki Kimura, Research, MOA Health Science Foundation, Atami, Shizuoka, Japan, Kiyoshi Suzuki, MOA Takanawa Clinic, Gyokusenkai, Tokyo, Japan, Seiya Uchida, Research, MOA Health Science Foundation, Atami, Shizuoka, Japan, Hiroshi Katamura, MOA Takanawa Clinic, Gyokusenkai, Tokyo, Japan

#### 253/1320/Choosing a Patient-Reported Outcome Measure

Leah M. McClimans, Philosophy, University of South Carolina, Columbia, SC, John P. Browne, Epidemiology and Public Health, University College Cork, Cork, Ireland

### 254/1715/Key Evidences Required to Support Content Validity for Patient Reported Outcome (PRO) Instruments Mona L. Martin, Health Research Associates, Mountlake Terrace, WA

### 255/1758/Assessing Relevance of Concepts to Support Content Validity for Patient Reported Outcome (PRO) Instruments

Mona L. Martin, Health Research Associates, Mountlake Terrace, WA

#### 256/1041/The Wheel of Life: a Novel Method for Exploring Health-related Quality of Life (HRQoL)

Jane Speight, AHP Research, Uxbridge, Middlesex, UK, Alison J. Woodcock, Psychology, Royal Holloway University of London, Egham, Surrey, UK

### 257/1628/The benefits of mixed methods in scale development I: The added value of Rasch analysis in pretesting

Claudia Gorecki, Clinical Trials Research Unit, University of Leeds, Leeds, West Yorkshire, UK, Donna L. Lamping, Health Services Research and Policy, London School of Hygiene & Tropical Medicine, London, United Kingdom, Jane Nixon, Julia M. Brown, Clinical Trials Research Unit, University of Leeds, Leeds, West Yorkshire, United Kingdom, Stefan Cano, Clinical Neurology Research Group, Peninsula College of Medicine and Dentistry, Plymouth, United Kingdom

### 258/1468/Using Choice-Format Conjoint Analysis to Assign Meaning to PRO Scores

Cheryl D. Coon, Patient-Reported Outcomes, A. Brett Hauber, Ateesha F. Mohamed, Health Preference Assessment, Lori D. McLeod, Patient-Reported Outcomes, RTI Health Solutions, Research Triangle Park, North Carolina

### 259/1630/Clustering of Health-Related Quality of Life (HRQoL) items in metastatic prostate cancer patients

Francesca Martinelli, Chantal Quinten, John Maringwa, Corneel Coens, Quality of Life, EORTC, Brussels, Belgium, Charles Cleeland, Symptom Research, U.T. M.D. Anderson Cancer Center, Houston, Texas, Carolyn Gotay, School of Population and Public Health, British Columbia University, Vancouver, Canada, Bryce Reeve, Cancer Control and Population Sciences, National Cancer Institute, Bethesda, Maryland, Jolie Ringash, The Princess Margaret Hospital, University of Toronto, Toronto, Canada, Henning Flechtner, Child and Adolescent Psychiatry and Psychotherapy, Medical Faculty of the Otto-von-Guericke-University, Magdeburg, Germany, Eva Greimel, Obstetrics and Gynecology, University of Graz, Graz, Austria, David Osoba, Quality of Life, Consulting, West Vancouver, Canada, Madeleine King, Psycho-oncology Co-operative Research Group, University of Sydney, Sidney, Australia, Joseph Schmucker-Von Koch, Medical Ethics Philosophical Faculty, University of Regensburg, Regensburg, Germany, Martin Taphoorn, VU Medical Center, Medical Center Haaglanden, The Hague, The Netherlands, Joachim Weis, Psychooncology, University of Freiburg, Freiburg, Germany, Sophie Fosså, Clinical Research, Oslo University Hospital, Oslo, Norway, Walter Albrecht, Urology, Landesklinikum Weinviertel Mistelbach, Mistelbach, Austria, Hendrik Van Poppel, Urology, University Hospitals Leuven, Leuven, Belgium, Philip Powell, Mark Johnson, Urology, Freeman Hospital, Newcastle, United Kingdom, Andrew Bottomley, Quality of Life, EORTC, Brussels, Belgium

#### 260/1734/Filling in the gaps: content validity for older guestionnaires

Jennifer R. Welle, Kimberly L. Miller, Rene M. Dickerhoof, Hilary H. Colwell, Lifecycle Science Group, ICON Clinical Research, San Francisco, CA

#### 261/1396/A systematic review process can inform our understanding of PRO

Joy C. MacDermid, Rehabilitation Science, McMaster University, Hamilton, Ontario, Canada

#### 262/1181/Parent-reported Perceived Cognitive Function Item Bank for Children

Jin-Shei Lai, Zeeshan Butt, Medical Social Sciences, Northwestern University, Chicago, IL, Frank Zelko, Children's Memorial Hospital, Chicago, IL, David Cella, Medical Social Sciences, Northwestern University, Chicago, IL, Stewart Goldman, Children's Memorial Hospital, Chicago, IL

### 263/1775/Developing initial item pools to measure quality of life for young adult survivors of childhood and adolescent cancer

I-Chan Huang, Pey-Shan Wen Wen, Epidemiology and Health Policy Research, Patricia Shearer Shearer, Pediatrics, Elizabeth Shenkman, Epidemiology and Health Policy Research, University of Florida, Gainesville, FL, Gwendolyn Quinn Quinn, Health Outcomes & Behavior, H. Lee Moffitt Cancer Center & Research Institute, Tampa, FL

### 264/1345/Examining the Implications of Sample Heterogeneity with Respect to the Measurement Validity of Computerized Adaptive Tests

Richard Sawatzky, Nursing, Trinity Western University, Langley, British Columbia, Canada, Pamela A. Ratner, Nursing, Jacek A. Kopec, Population and Public Health, Amery Wu, Nursing, Bruno D. Zumbo, ECPS, Measurement, Evaluation & Research Methodology, University of British Columbia, Vancouver, British Columbia, Canada

### 265/1453/Do printed symptom reports improve symptom control? A longitudinal controlled trial of PROs in patients receiving chemotherapy

Erik K. Fromme, Medicine, Radiation Medicine, and Nursing, Tawni Kenworthy-Heinige, Katherine Hall, Medicine, Lillian M. Nail, School of Nursing, Tom M. Beer, Susan W. Tolle, Medicine, Oregon Health & Science University, Portland, OR

#### 266/1497/Development of a Computerized Outcome Assessment Tool for Head and Neck Cancer Patients

Joseph T. Chang, Radiation Oncology, Hung-Ming Wang, Hematology and Medical Oncology, Chien-Yu Lin, Radiation Oncology, Chang Gung University, Taoyuan, Taiwan, Taiwan, Chih-Hung Chang, Methodology and Infometrics Section, Northwestern University, Chicago, IL

#### 267/1552/Doctors' evaluation of HRQoL electronic data collection

Alexandra Oliveira, Foundation for Sciences and Techhology, Health Sciences, University of Aveiro, Aveiro, Portugal, Pedro L. Ferreira, Centre for Health Studies & Research, Faculty of Economics, University of Coimbra, Coimbra, Portugal, Francisco L. Pimentel, Health Sciences, University of Aveiro, Aveiro, Portugal

### 268/1613/Development and Use of Touch-Screen Computer-Assisted Self Interviewing in Portuguese Patients with Chronic Immune Diseases: An Inicial Evaluation of NA Electronic Version of SF-36v2

Cláudia Ribeiro, Health Sciences, Hospital Santo António, Universidade Católica Portuguesa, 3504-505 Viseu, Portugal, Portugal, Luis Moreira PhD, Informatics, Instituto Piaget, Vila Nova de Gaia, Portugal, Augusta Silveira, Health Sciences, Fernando Pessoa University, POrto, Portugal, Isabel Silva, Faculdade de Ciências Humanas e Sociais, Universidade Fernando Pessoa, Porto, Portugal, Gestal Otero, Servicio de Medicina Preventiva y Salud Pública, Hospital Clínico Universitario Santiago Compostela, Santiago de Compostela, Spain, Carlos Vasconcelos, Head of Unidade de Imunologia Clínica, Hospital Santo António, Porto, Portugal

#### 269/1216/An Audio Urdu LupusQoL in clinic

Lee Suan Teh, Suresh Adimulam, Diptasri Sen, Rheumatology, Royal Blackburn Hospital, Blackburn, UK, Caroline Gordon, Kanta Kumar, Rheumatology, University of Birmingham, Birmingham, UK, Ian N. Bruce, Johanna Shelmerdine, Rheumatology, University of Manchester, Manchester, UK, Kathleen McElhone, Rheumatology, Royal Blackburn Hospital, Blackburn, UK, Janice Abbott, Psychology, University of Central Lancashire, Preston, UK

#### 270/1365/Uncertainty in Systemic Lupus Erythematosus (SLE): Development of a Conceptual Model

Sophie Cleanthous, Unit of Behavioural Medicine, University College London, London, UK, Michael Shipley, David Isenberg, Centre for Rheumatology, University College London Hospital, London, UK, Stanton Newman, Unit of Behavioural Medicine, University College London, London, UK, Stefan Cano, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, UK

#### 271/1484/The Influence of Decision Making Behavior on Outcomes Reflecting Quality of Life

Penny F. Pierce, Maria C. Katapodi, School of Nursing, University of Michigan, Ann Arbor, Michigan

### 272/1673/Understanding the Burden of Treatment in Patients with Multiple Chronic Conditions: Evidence from Exploratory Interviews

David T. Eton, Health Sciences Research, Mayo Clinic, Rochester, MN, Djenane R. Oliveira, Medication Therapy Management, Fairview Pharmacy Services & University of Minnesota, Minneapolis, MN, Jason Egginton, Health Sciences Research, Mayo Clinic, Rochester, MN, Frances S. Mair, General Practice & Primary Care, University of Glasgow, Glasgow, UK, Carl May, Institute of Health & Society, Newcastle University Medical School, Newcastle upon Tyne, UK, Victor M. Montori, Knowledge & Encounter Research Unit, Mayo Clinic, Rochester, MN

### 273/1492/Assessing the added value of performing interaction analysis on focus group data generated to identify important and relevant HRQoL domains

Yen Ling Mandy Ow, Pharmacy, National University of Singapore, Singapore, Singapore, Singapore, Julian Thumboo, Rheumatology & Immunology, Singapore General Hospital, Singapore, Singapore, Singapore, Yin Bun Cheung, Biostatistics, Singapore Clinical Research Institute, Singapore, Singapore, Singapore, Kok-Yong Fong, Rheumatology & Immunology, Singapore General Hospital, Singapore, Singapore, 169608, Hwee Lin Wee, Pharmacy, National University of Singapore, Singapore, Singapore, Singapore

#### **Population & Policy**

#### 274/1521/Height and quality of life in ethnic Chinese: An observational study

Hwee Lin Wee, Pharmacy, National University of Singapore, Singapore, Singapore, Yin Bun Cheung, Biostatistics, Singapore Clinical Research Institute, Singapore, Singapore, Nan Luo, Epidemiology and Public Health, National University of Singapore, Singapore, Singapore, Chee Beng Tan, Geylang Polyclinic, Singapore Health Services, Singapore, Singapore, Kok-Yong Fong, Rheumatology & Immunology, Singapore General Hospital, Singapore, Singapore, Yen Ling Mandy Ow, Pharmacy, National University of Singapore, Singapore, Singapore, Julian Thumboo, Rheumatology & Immunology, Singapore General Hospital, Singapore, Singapore

#### 275/1066/Gender Inequalities in Quality of Life in Iran

Maryam Tajvar, Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, UK, MOHAMMAD

ARAB, Health Management and Economics Sciences, ALI MONTAZERI, Health Scinces Research Centre, Tehran University of Medical Sciences, Tehran, IRAN

### 276/1196/Differences in the Quality of Life of patients with Chronic Obstructive Pulmonary Disease between Brazil and Spain

Juliana Maria S. Pinto, Physiotherapy, University of Salamanca, Salamanca, Salamanca, Spain, Maria Teresa A. Pessoa Morano, Physiotherapy, Messejana s Hospital, Fortaleza, Ceará, Brazil, Ana María M. Nogueras, Physiotherapy, Jacinto R. González, Medicine, University of Salamanca, Salamanca, Salamanca, Spain, Amanda S. Araújo, Physiotherapy, Messejana s Hospital, Fortaleza, Ceará, Brazil

### 277/1225/Quality of Life and Frailty in older Brazilians: results from the SABE study - a 6 year follow up survey in São Paulo, Brasil.

Jair Licio F. Santos, Social Medicine, University of São Paulo, Ribeirão Preto, São Paulo, Brazil, Maria L. Lebrão, Epidemiology, University of São Paulo, SP, Brazil

### 278/1227/Follow up about QOL of all islander who live in a remote island (Ohshima island) of Japan

Kazuhiro Murata, Rehabilitation and Primary Care, Yame Rehabilitation Hospital, Yame City, Fukuoka Prefecture, Japan, Masanori Harada, Center for Community Medicine, Jichi Medical University, Shimotsuke City, Tochigi Prefecture, Japan

### 279/1230/Perceving quality of life and emerging life worries of Chinese child caregivers in Hong Kong: A mixed method study

Christine Mei Sheung Chan, Magdalena Mo Ching MOK, Psychological Studies, The Hong Kong Institute of Education, Hong Kong, Hong Kong

### 280/1780/Measuring Health-Related Quality of Life (SF-36) among Chinese Caregivers in Preschool Settings in Hong Kong

Christine Mei Sheung Chan, Magdalena Mo Ching MOK, Psychological Studies, The Hong Kong Institute of Education, Hong Kong, Hong Kong

#### 281/1250/Utilising SEIQoL-DW to evaluate and enhance Indigenous programs in the Northern Territory

Rachael J. McMahon, Kate A. Senior, Healing and Resilience Division, Menzies School of Health Research, Casuarina, Darwin, Northern Territory, Australia

#### 282/1726/Health related Quality of Life and dietary patterns in middle age French population

Lucie Germain, Epidémiologie et Evaluation Cliniques, CHŪ Nancy, Vandoeuvre-lès-Nancy, France, Clotilde LATARCHE, EA 4360 APEMAC, Nancy-Université, Vandoeuvre-lès-Nancy, France, Emmanuelle KESSE-GUYOT, Pilar GALAN, Serge HERCBERG, UREN, Université Paris 13, Bobigny, France, Serge BRIANÇON, EA 4360 APEMAC, Nancy-Université, Vandoeuvre-lès-Nancy, France

### 283/1493/Nationwide survey of awareness and understanding of quality of life in Japan: A comparison of surveys in 2004 and 2010

Kikuko Miyazaki, Health Informatics, Kyoto University School of Public Health, Kyoto, Kyoto, Japan, Yoshimi Suzukamo, Physical Medicine and Rehabilitation, Tohoku University Graduate School of Medicine, Sendai, Miyagi, Japan, Kojiro Shimozuma, Life Sciences, Ritsumeikan University, Kusatsu, Shiga, Japan, Fumi Hayashi, Human Sciences, Toyo-Eiwa University, Yokohama, Kanagawa, Japan, Mari Saito, General Medicine, Yokohama City University, Yokohama, Kanagawa, Japan, Takeo Nakayama, Health Informatics, Kyoto University School of Public Health, Kyoto, Kyoto, Japan

### 284/1419/The WHOQOL-BREF questionnaire: Psychometric properties of the Turkish National Data Pool 2000-2010.

Erhan Eser, Public Health, Celal Bayar University, Manisa, Turkey, HAKAN BAYDUR, Public Health, Dokuz Eylül University, Ozmir, Turkey

### 285/1080/Health Related Quality of Life Measured by SF-36v2: A Population-Based Study In Portuguese Patients with Disorders of the Immune System

Claudia C. Ribeiro, Imunologia Clinica, Hospital Santo Antonio - Centro Hospitalar do Porto, Viseu, Portugal, Isabel Silva, Psicologia, Universidade Fernando Pessoa, Porto, Portugal, Luis Moreira, Estatistica, Instituto Piaget, Vila Nova de Gaia, Portugal, Augusta Silveira, Ciencias da Saude, Universidade Fernando Pessoa, Porto, Portugal, Gestal Otero, Servicio de Medicina Preventiva y Salud Pública, Universidade Santiago Compostela, Santiago Compostela, Espanha, Carlos Vasconcelos, Head of Unidade de Imunologia Clínica, Hospital Santo António, Porto, Portugal

#### 286/1107/The association between Health-Related Quality of Life and anxiety in a Greek adult population

Eleni Theodoropoulou, Nektarios A. Stavrou, Konstantinos Karteroliotis, Physical Education and Sports Science, National and Kapodistrian University of Athens, Athens, Greece

### 287/1496/Frailty and Health Related Quality of Life in A Community-Based Elders in Taiwan

Tsai-Chung Li, Graduate Institute of Biostatistics, Cheng-Chieh Lin, Family Medicine, Chin-Kai Chang, Physical Medicine and Rehabilitation, China Medical University and Hospital, Taichung, Taiwan, R.O.C., Yu-Chun Chang, Medical Research, Yi-Wen Chiu, Community Medicine, China Medical University Hospital and Hospital, Taichung, Taiwan, R.O.C., Ming-May Lai, Family Medicine, China Medical University and Hospital, Taichung, Taiwan, R.O.C.

#### 288/1086/Estimating HR-QOL and Longevity Using the "Illness-death" Model

Michael T. Molla, Epidemiology/Demography, U.S. National Center for Health Statistics, Hyattsville, Maryland

#### 289/1813/Outcome Measure for the Long-term Care

Raymond Ostelo, Epidemiology and Biostatistics, EMGO, VU University Amsterdam, Amsterdam, The Netherlands, Bernard van den Berg, Health Sciences, VU University, Amsterdam, Amsterdam, The Netherlands, Henrica de Vet, Epidemiology and Biostatistics, EMGO, VU University Amsterdam, Amsteradm, The Netherlands, Rein Vos, Health, Ethics and Society, Maastricht University, Maastricht, The Netherlands

### 290/1736/Quality of Life and Urinary Incontinence in Elderly with Criteria of Frailty in an Ambulatory Care Vanessa A. da Silva, Déborah C. Oliveira, Maria J. D'Elboux, Nursing Departament, State University of Campinas, Campinas, S.

Vanessa A. da Silva, Déborah C. Oliveira, Maria J. D'Elboux, Nursing Departament, State University of Campinas, Campinas, São Paulo, Brazil

#### 291/1755/Association between SF-12 and basic and instrumental activities of daily living in older adults

Keila Cruz, MARIA JOSÉ D´ELBOUX, NURSING, UNIVERSIDADE ESTADUAL DE CAMPINAS, CAMPINAS, SÃO PAULO, BRAZIL, Yeda Duarte, Nursing, Universidade de São Paulo, SÃO PAULO, SÃO PAULO, Brazil, MARIA LUCIA LEBRÃO, EPIDEMILOGY, UNIVERSIDADE DE SÃO PAULO, CAMPINAS, SÃO PAULO, BRAZIL

#### 292/1444/Life Quality Evaluation of Elderly Men Living In South of Minas

José V. Silva, LUCIANO M. VITORINO, DANIEL MACHADO, NURSING, SCHOOL OF NURSING WENCESLAU BRAZ, ITAJUBÁ, MINAS GERAI, BRAZIL, EWERTON N. DIAS, FERNANDO M. VITORINO, NURSING, SCHOOL OF NURSING WENCESLAU BRAZ, ITAJUBÁ, MINAS GERAIS, BRAZIL

#### 293/1513/The Association of Probable Depression and Frailty in Elderly Taiwanese

Cheng-Chieh Lin, Chih-Hsueh Lin, Family Medicine, Cha-Zin Chan, Medical Research, Tsai-Chung Li, Graduate Institute of Biostatistics, Wen-Yuan Lin, Family Medicine, China Medical University and Hospital, Taichung, Taiwan, R.O.C.

### 294/1515/Successful Aging Defined by Health-Related Quality of Life and Its Determinants in Elderly Taiwanese

Chia-Ing Li, Medical Research, China Medical University Hospital and Hospital, Taichung, Taiwan, R.O.C., Nai-Hsin Meng, Physical Medicine and Rehabilitation, Chiu-Shong Liu, Family Medicine, China Medical University and Hospital, Taichung, Taiwan, R.O.C., Fang-Mien Tsai, Family Medicine, China Medical University Hospital and Hospital, Taichung, Taiwan, R.O.C., Cheng-Chieh Lin, Family Medicine, Tsai-Chung Li, Graduate Institute of Biostatistics, Chuan-Wei Yang, Medical Research, China Medical University and Hospital, Taichung, Taiwan, R.O.C.

#### 295/1279/Quality of Life Model: Predictors of Quality of Life among Older Adults

Liv Halvorsrud, Nursing Department, Diakonova Univerisity College, Oslo, Norway, Marit Kirkevold, Institute of Nursing and Health Sciences, Faculty of Medicine, University of Oslo, Oslo, Norway, Åge Diseth, Faculty of Psychology, University of Bergen, Bergen, Norway, Mary Kalfoss, Nursing Department, Diakonova University College, Oslo, Norway

### 296/1297/Impact of treatment and metabolic control on Quality Of Life of Adolescents with Type 1 Diabetes Mellitus

Tatiana S. de Sá Novato, Sonia A. Grossi, Medical Surgical Nursing, University of São Paulo, São Paulo, São Paulo, Balduino Tschiedel, Márcia K. Coutinho, Silvana E. Speggiorin, Ana M. Ferreira, Institute for Children With Diabetes, Nossa Senhora da Conceição Hospital, Porto Alegre, Rio Grande do Sul, Brazil

### 297/1182/Validation of the modified 1-week recall version of the Pediatric Quality of Life Inventory 3.2 (PedsQL) Type 1 Diabetes Module

April N. Naegeli, Bradley H. Curtis, Global Health Outcomes, Eli Lilly and Company, Indianapolis, IN, David A. Bryant, Health Services Research, Synovate, Falls Church, VA, Risa P. Hayes, Global Health Outcomes, Eli Lilly and Company, Indianapolis, IN

### 298/1756/Measurement properties of a quality of life instrument for youth who are deaf or hard of hearing (YQOL-DHH)

Donald L. Patrick, Todd C. Edwards, Anne M. Skalicky, Health Services, University of Washington, Seattle, WA, Mei Leng, General Internal Medicine, Los Angeles, CA, Tari D. Topolski, Health Services, University of Washington, Seattle, WA, Brenda Schick, Speech, Language and Hearing Sciences, University of Colorado, Boulder, CO, Poorna Kushalnagar, Health Services, University of Washington, Seattle, WA, Kathleen Sie, Pediatric Otolaryngology, Seattle Children's Hospital, Seattle, WA

#### 299/1754/Perceptions of Quality of Life among Youth who are Deaf or Hard of Hearing

Anne M. Skalicky, Poorna Kushalnagar, Tari D. Topolski, Health Services, University of Washington, Seattle, WA, Brenda Schick, Speech, Language and Hearing Sciences, University of Colorado, Boulder, CO, Todd C. Edwards, Health Services, University of Washington, Seattle, WA, Kathleen Sie, Division of Pediatric Otolaryngology, Seattle Children's Hospital, Seattle, WA, Donald L. Patrick, Health Services, University of Washington, Seattle, WA

### 300/1313/Longitudinal assessment of health related quality of life via child and parent-proxy reports in children with thalassemia following hematopoietic stem cell transplantation

Giovanni Caocci, Bone Marrow Transplant Center, R. Binaghi Hospital, Cagliari, Italy, Fabio Efficace, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases GIMEMA, Roma, Italy, Francesca Ciotti, Maria Grazia Roncarolo, Pediatric Immuno-Hematology and BMT Unit, IRSS San Raffaele Hospital, Milano, Italy, Adriana Vacca, Eugenia Piras, Bone Marrow Transplant Center, R. Binaghi Hospital, Cagliari, Italy, Raji S. Dawood, Thalassemia Centre, Hevi Pediatric Hospital, Duhok, Iraq, Gary C. Collins, Centre for Statistics in Medicine, University of Oxford, Oxford, UK, Fabio Ciceri, Pediatric Immuno-Hematology and BMT Unit, IRSS San Raffaele Hospital, Milano, Italy, Franco Mandelli, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases GIMEMA, Roma, Italy, Sarah Marktel, Pediatric Immuno-Hematology and BMT Unit, IRSS San Raffaele Hospital, Milano, Italy, Giorgio La Nasa, Bone Marrow Transplant Center, R. Binaghi Hospital, Cagliari, Italy

### 301/1708/What is the Health-related quality of life of caregivers of patients with Juvenile Idiopathic Arthritis like?

Tania Maria S. Mendonça, Pediatrics, Universidade Federal de Uberlândia, Uberlândia, Minas Gerais, Brazil, Len A. Cláudio, Hilario E. Maria Odete, Pediatrics, Universidade Federal de São Paulo, São Paulo, São Paulo, Brazil, Silva M. Carlos Henrique, Paro S. Martins Helena, Pediatrics, Pinto M. Costa Pinto, Mathematics, Universidade Federal de Uberlândia, Uberlândia, Minas Gerais, Brazil

### 302/1773/The impact of disease activity and damage on quality of life in systemic lupus erythematosus (SLE) assessed by the LupusQoL questionnaire

Chi Chiu Mok, Medicine, Tuen Mun Hospital, Hong Kong, Hong Kong, Kathleen McElhone, Lee Suan Teh, Rheumatology, Royal Blackburn Hospital, London, United Kingdom

#### 303/1610/Children with chronic diseases quality of life and biomedical ethics principles

Estelle Boetti, Pascal Auquier, Public Health, Nord University Hospital, Marseille, France, Pierre Le Coz, Medical Philosophy, La Timone University Hospital, Marseille, France, Marie-Claude Simeoni, Public Health, Nord University Hospital, Marseille, France

#### 304/1728/Families Needs seeking quality of life in children with spinal muscular atrophy

Caroline S. Nobre, Fatima Luna Pinheiro Landim, NURSING, MIRNA A. FROTA, INGRID MARIA M. ALVES, VANESSA G. SILVEIRA, PUBLIC HEALTH, UNIVERSITY OF FORTALEZA, FORTALEZA, CEARA, BRAZIL, LUIZA LUANA A. LIRA, NURSING, PUBLIC HEALTH, FORTALEZA, CEARA, BRAZIL, CINTIA F. CASIMIRO, NURSING, UNIVERSITY OF FORTALEZA, FORTALEZA, CEARA, BRAZIL

### 305/1577/Development of a Pediatric Chronic Constipation Symptom Measures: Results of Qualitative Interviews with Children and Their Parents

Linda Abetz, Rob Arbuckle, PRO, Mapi Values Ltd, Bollington, Cheshire, UK, Robyn Carson, Health Economics & Outcomes Research, Forest Research Institute, Jersey City, NJ, Barbara Lewis, Health Economics and Outcomes Research, Iron Pharmaceuticals, Cambridge, MA, Laura-Jayne Hunter, PRO, Mapi Values Ltd, Bollington, Cheshire, UK, Steven J. Shiff, Clinical Development, Forest Research Institute, Jersey City, NJ, Jeffrey Johnston, Ironwood Pharmaceuticals, Cambridge, MA

#### 306/1743/Quality of Life of Children with Cerebral Palsy

Caroline S. Nobre, NURSING, Ana Maria Fontenele Catrib, MIRNA A. FROTA, NURSING, UNIVERSITY OF FORTALEZA, FORTALEZA, CEARA, BRAZIL, VIVIANE M. VASCONCELOS, NURSING, FEDERAL UNIVERSITY OF CEARA, FORTALEZA, CEARA, BRAZIL, ISABELLY C. LIMA DE OLIVEIRA, NURSING, UNIVERSITY OF FORTALEZA, CAUCAIA, CEARA, BRAZIL, VANESSA G. SILVEIRA, NUTRICION, LUIZA LUANA A. LIRA, CONCEIÇÃO M. ALBUQUERQUE, NURSING, UNIVERSITY OF FORTALEZA, FORTALEZA, CEARA, BRAZIL

### 307/1402/Undergoing external fixator treatment for lower limb deformities in children and teens: What about quality of life?

Noémi Dahan-Oliel, Rehabilitation Science, McGill University, Montreal, Quebec, Canada, Kathleen Montpetit, Occupational Therapy, Shriners Hospital for Children, Montreal, Quebec, Canada, Unni Narayanan, Pediatrics, Hospital for Sick Children, Toronto, Ontario, Canada, Hamdy Reggie, Orthopedic surgery, Shriners Hospital for Children, Montreal, Quebec, Canada

### 308/1753/Comparative Study of Health-Related Quality of Life of Children and Adolescents with Disabling Neurological Disease

Nívea M O. Morales, of Surgery, Neurologic Propedeuthic Division, Carlos H M. Silva, Pediatrics, Carlos H A. Rezende, Medical Clinic, Anna Flávia O. Santana, Medicine, Rogério M C. Pinto, Mathematics, Rogério R. Morales, Neurology, Mariza M. Cuvero, Eliane M. Santos, Luíz D. U. Rocha-Júnior, Danielle M. Morais, Myrciara M. Alcântara, Medicine, Universidade Federal de Uberlândia, Uberlândia, Minas Gerais, Brazil

### 309/1747/Do disabling neurological diseases in childhood cause a different impact on the mothers quality of life?

Carlos Henrique M. Silva, Medicine, Nívea de M. O. Morales M. Morales, Pediatric, Carlos Henrique A. Rezende, Ana Karine M. Rodrigues, Priscilla S. Lima, Rogério M. Pinto, Mariza M. Cuvero, Eliane M. Santos, Luiz D. Junior, Danielle M. Morais, Medicine, University of Uberlandia, Uberlandia, Minas Gerais, Brazil

#### 310/1501/Cultural adaptation and validation of "Diabetes Quality of Life for Youths"

Tatiana S. Novato, Sonia A. Grossi, Miako Kimura, Medical Surgical Nursing, University of São Paulo, São Paulo, São Paulo, Brazil

### 311/1723/Cross-cultural adaptation and preliminary validation of the Cystic Fibrosis Questionnaire (CFQ) in Spanish language (Child and Parent versions)

Macarena M. Anchóriz, Hospital Universitario Virgen del Rocío, Universidad de Sevilla, Sevilla, Spain, Montserrat M. Gómez de Terreros, Facultad de Psicología, Universidad de Sevilla, Sevilla, España

#### 312/1607/Sibling Support & Adjustment to Parental Neurological Illness

David Morley, Psychology, Thames Valley University, Brentford, Middlesex, UK, Caroline Selai, Alan Thompson, Institute of Neurology, University College London, Queen Square, London, United Kingdom

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Pfizer (support for Friday Plenary session "The Routine Use of Patient-reported Outcome Measures in Health Service Decision Making: Challenges and Opportunities")

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> Chair: Galina Velikova G.Velikova@leeds.ac.uk

Membership issues: **Susanne Singer** sins@medizin.uni-leipzig.de

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### What's in it for me?

- \* You become part of an international network of people who are working in a similar field to your own;
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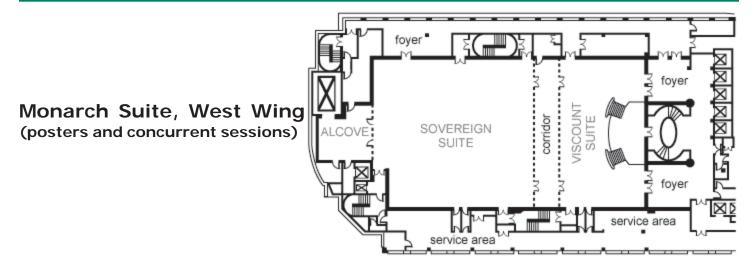
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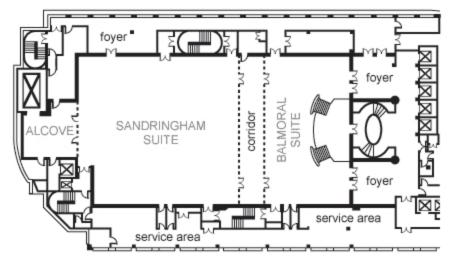
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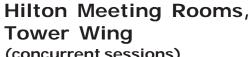


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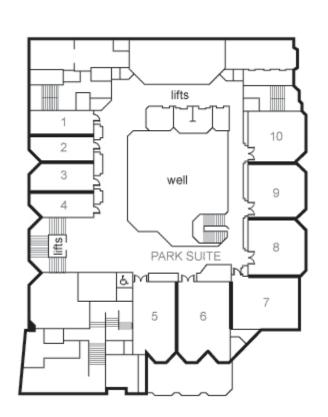


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