

Hotel Floor Plan

Ground Floor



Second Floor



Conference WiFi network:
claytonhotelwifi no password required

Welcome to the 25th Annual Conference of the International Society for Quality of Life Research 24-27 October 2018



PROs in the digital age: New frontiers in research, policy and practice

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ISOQOL Office

555 E. Wells Street, Suite 1100
Milwaukee, WI 53202, United States
Telephone: +1(414) 918-9797 Fax: +1(414) 276-3349
E-mail: info@isoqol.org Web: www.isoqol.org

Clayton Hotel Burlington Road

4 Upper Leeson Street
Dublin 4, D04 A318 Ireland
TEL: +353 1 618 5600
Info.burlingtonroad@claytonhotels.com

Welcome from the Scientific Program Chairs

Céad Míle Fáilte!

A hundred thousand welcomes to Dublin, Ireland! As Scientific Program Co-Chairs, we would like to welcome you to the 25th Annual Conference of the International Society for Quality of Life Research. This year's conference theme is: "PROs in the digital age: New frontiers in research, policy and practice". We have a stimulating scientific program featuring four plenary sessions that explore different aspects of PROs in today's digital landscape.

Thursday's first plenary "Digital self-tracking to support patient self-management" explores the digital collection and use of PRO data by patients, along with opportunities and challenges of digital self-tracking from multiple perspectives. The second plenary session will feature "Cutting Edge Research" – some of the most innovative and highest ranked research submitted to ISOQOL this year.

Digital data capture is now commonplace in everyday life – from public and patients recording health data using apps and digital tracking devices to evaluating consumer data from our online purchases. On Friday during "Big data to support research and health care" speakers address the opportunities and challenges presented by big data.

On Saturday, we consider what the use of PROs in the digital age means for the concept of validity and how we apply PROs in drug development and trials during "Generalizability of validity data across diseases and treatment settings: when is enough, enough?"

In addition to the plenary sessions, a number of exciting preconference education opportunities are offered, including: eight half-day workshops, the Introduction to Patient Reported Outcomes (IPRO) Course, and the new Intro to PCOR for Pharma/Biotech (IPCOR-Pharma) Course.

Join us at the welcome reception as we toast the past 25 years of ISOQOL, celebrate the achievements of the Society, and look ahead to the future of PRO development and application in research and practice. The welcome reception will include a ceremonial cake cutting, beverage toast, recognition of past leaders, photo booth, and more. A complimentary beverage voucher can be found in your registration packet (*valid during the welcome reception only*). This is a celebration you won't want to miss!

With exciting changes to our conference registration, this is the first time every conference attendee is a member of ISOQOL! All are welcome to join us at the Member Business Meeting on Saturday morning as leadership shares an update on the endeavors of the Society in 2018. This year a buffet lunch is also provided to conference attendees on Thursday, Friday and Saturday (see lunch schedule on page 8).

This conference will also feature many of the same exceptional programs from prior years that encourage networking and camaraderie. ISOQOL is continuing our SIG Meetings which provide members an outlet to collaborate with others who share similar interests. The mentor/mentee reception and roundtables provide an informal setting for attendees to interact with major field influencers.

Finally, remember to register for the Closing Dinner on Saturday if you have not already done so! An exclusive venue in the heart of Dublin opened in 1860, No. 6 Kildare Street has been home to the Royal College of Physicians of Ireland for over 150 years and has a unique collection of artifacts and antiques which reflect the rich history of the College. A limited number of seats remain; visit the registration desk to purchase a ticket.

While you're in Dublin, we encourage you to use the conference mobile app (page 13) to plan your personal schedule for both conference sessions and your adventures around the city!



Joanne Greenhalgh, PhD and Diana Rofail, PhD, CPsychol
2018 Scientific Program Committee Co-Chairs

Schedule at a Glance

Wednesday, 24 October 2018

9:00 am - 12:00 pm	Morning Workshops* (WK01 – WK04)	
	WK01: Interpretation guidelines to define clinical relevance for Patient-Reported Outcome (PRO) measures	Meeting Room 6
	WK02: Multilevel Data: A Look at Psychometric Analyses	Meeting Room 9
	WK03: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice?	Meeting Room 2
	WK04: Group Concept Mapping: Engaging Patients as Outcome Framework Co-Authors	Meeting Room 5
9:00 am - 4:00 pm	Intro to Patient-Reported Outcomes (IPRO Course)*	Meeting Room 1
9:00 am - 4:00 pm	Intro to PCOR for Pharma/Biotech (IPCOR-Pharma Course)*	Meeting Room 7
1:00 pm - 4:00 pm	Afternoon Workshops* (WK05 – WK08)	
	WK05: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions	Meeting Room 5
	WK06: Clinical outcome assessments embedded in mobile and wearable information technologies	Meeting Room 6
	WK07: Back to the roots: the importance of applying theory to patient-reported outcomes measures (PROMs) validity testing	Meeting Room 2
	WK08: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Approaches for Data collection, Analyses and Reporting	Meeting Room 9
4:30 pm - 6:00 pm	Industry SIG (I-SIG) Symposium	Pembroke & Herbert
	Meaning in movement: Defining valid endpoints using data collected with mobile technology tools	
6:00 pm - 7:30 pm	Welcome Reception & 25th Celebration	Fitzwilliam Suites

* Event requires additional cost and preregistration to attend.

Schedule at a Glance

Thursday, 25 October 2018

7:30 am - 8:00 am	First Time Attendee - Coffee with Board of Directors	Meeting Room 1+2
8:15 am - 8:30 am	Welcome from Co-Chairs	Pembroke & Herbert
8:30 am - 10:00 am	Plenary 1: Digital self-tracking to support patient self-management	Pembroke & Herbert
10:10 am - 10:45 am	Thursday Poster Session I	Lansdowne Room
10:50 am - 12:00 pm	Plenary 2: Cutting Edge Research	Pembroke & Herbert
12:00 pm - 1:45 pm	Buffet Lunch (included in conference registration) Lunch Shifts 12:05 pm and 1:00 pm	Sussex Restaurant
12:10 pm - 1:05 pm	Committee/SIG Meetings	
	Child Health SIG Meeting	Meeting Room 1+2
	Health Preference Research SIG Meeting	Meeting Room 9
	Industry SIG Meeting	Meeting Room 5
	Mixed Methods SIG Meeting	Meeting Room 6
	Patient Engagement SIG Meeting	Pembroke & Herbert
1:45 pm - 3:15 pm	Concurrent Oral Sessions	
	101: Interpreting Meaningful Change	Meeting Room 1+2
	102: Health Utilities	Meeting Room 6
	103: Mobile Applications	Meeting Room 9
	104: Holistic Measurement in Dementia and Alzheimer's Disease	Pembroke & Herbert
3:25 pm - 4:00 pm	Thursday Poster Session II	Lansdowne Room
4:05 pm - 5:35 pm	Concurrent Oral Sessions	
	105: Paediatrics	Meeting Room 1+2
	106: Cancer	Pembroke & Herbert
	107: Mapping and Linking Across Measures	Meeting Room 9
	108: Digital Health Technologies	Meeting Room 6
5:50 pm - 6:20 pm	Tricks of the Trade Presentation	Pembroke & Herbert
6:30 pm - 7:30 pm	Mentor/Mentee Reception *	Munster & Leinster

* Event requires additional cost and preregistration to attend.

Schedule at a Glance

Friday, 26 October 2018

7:45 am - 8:45 am	SIG Council Meeting (closed event)	Meeting Room 1+2
7:45 am - 8:45 am	Roundtables*	
	RT01: Interpretability of PROs in clinical practice	Meeting Room 5
	RT02: Identifying responders to treatment	Meeting Room 5
	RT03: The EORTC QLQ-C30: Past, present and future	Meeting Room 6
	RT04: Online monitoring of symptoms and side-effects during cancer treatment	Meeting Room 6
	RT05: Maximizing the uptake and implementation of SPIRIT-PRO Guidance	Meeting Room 6
	RT06: Identifying dogmas in quality-of-life research: How to enrich our field	Meeting Room 7
	RT07: PRO-PMs (PRO-based performance measures)	Meeting Room 7
	RT08: Smashing the glass ceiling – Women in leadership	Meeting Room 9
	RT09: Patient-centered research to support product development in the pharmaceutical industry	Meeting Room 9
	RT10: PROs in clinical trials - what could possibly go wrong?	Meeting Room 9
9:00 am - 10:30 am	Plenary 3: Big data to support research and health care	Pembroke & Herbert
10:35 am - 11:10 am	Friday Poster Session I	Lansdowne Room
11:15 am - 12:30 pm	Concurrent Symposium Sessions	
	Symposium 1: Minimising Research Waste and Maximising the Impact of Patient Reported Outcome Trial Results	Pembroke & Herbert
	Symposium 2: Clinical outcomes assessment use in rare disease studies: Real life examples from clinicians, patient advocates, industry, and measurement experts	Meeting Room 1+2
	Symposium 3: Challenges in itembanking - future perspectives on development and application	Meeting Room 9
	Symposium 4: Using PROs and Machine Learning to identify “at risk” patients for musculoskeletal injury	Meeting Room 6
12:30 pm - 2:00 pm	Buffet Lunch (included in conference registration) Lunch Shifts 12:30 pm and 1:15 pm	Sussex Restaurant
12:35 pm - 1:30 pm	Committee/SIG Meetings	
	Australia and New Zealand SIG Meeting	Meeting Room 5
	Canada PRO SIG Meeting	Meeting Room 6
	Psychometrics SIG Meeting	Pembroke & Herbert
	United Kingdom and Ireland SIG Meeting	Meeting Room 9
2:00 pm - 3:30 pm	Concurrent Oral Sessions	
	201: Response Shift	Meeting Room 1+2
	202: Meeting the Needs of Stakeholders	Meeting Room 6
	203: Clinical Trial Methods	Pembroke & Herbert
	204: Underresearched Populations	Meeting Room 9
3:35 pm - 4:10 pm	Friday Poster Session II	Lansdowne Room
4:15 pm - 5:45 pm	Concurrent Oral Sessions	
	205: Psychometrics	Meeting Room 1+2
	206: PROs in Clinical Practice	Pembroke & Herbert
	207: Daily PRO Measurement	Meeting Room 9
	208: Missing Data	Meeting Room 6

* Event requires additional cost and preregistration to attend.

Schedule at a Glance

Saturday, 27 October 2018

8:00 am - 8:30 am	President's Address	Pembroke & Herbert
8:30 am - 9:45 am	ISOQOL Member Business Meeting	Pembroke & Herbert
9:45 am - 10:15 am	Saturday Poster Session I	Lansdowne Room
10:15 am - 11:00 am	Awards Presentation & 2019 Conference Announcement	Pembroke & Herbert
11:00 am - 12:30 pm	Plenary 4: Generalizability of validity data across diseases and treatment settings: When is enough, enough?	Pembroke & Herbert
12:30 pm - 2:00 pm	Buffet Lunch (included in conference registration) Lunch Shifts 12:30 pm and 1:15 pm	Sussex Restaurant
12:35 pm - 1:30 pm	Committee/SIG Meetings	
	Ibero America SIG	Meeting Room 5
	New Investigator SIG	Meeting Room 9
	QOL in Clinical Practice SIG	Pembroke & Herbert
	Response Shift SIG	Meeting Room 1+2
	Translation and Cultural Adaptation SIG	Meeting Room 6
2:00 pm - 3:15 pm	Symposium Sessions	
	Symposium 5: What Matters to You: Measuring Patient Experiences	Pembroke & Herbert
	Symposium 6: A PRO-cision Medicine Toolkit: Methods for Aiding Interpretation of and Acting on PRO Scores in Clinical Practice	Meeting Room 1+2
	Symposium 7: Role of Health Preferences in Clinical Decision Making: The Past, Present, and Future	Meeting Room 9
	Symposium 8: Methods for Scoring that Maximize Sensitivity to Treatment Effects: Three Major Pitfalls and How to Avoid Them	Meeting Room 6
3:15 pm - 3:45 pm	Saturday Poster Session II	Lansdowne Room
3:50 pm - 5:20 pm	Concurrent Oral Sessions	
	301: Cancer Survivorship	Meeting Room 1+2
	302: Surveys and Longitudinal Studies	Meeting Room 6
	303: Heterogeneity and Meaning in Measurement	Meeting Room 9
	304: Qualitative Methods in Instrument Development	Pembroke & Herbert
7:00 pm - 10:00 pm	Closing Dinner*	Off-site

* Event requires additional cost and preregistration to attend.

General Conference Information

Conference Theme:

"PROs in the digital age: New frontiers in research, policy and practice"

Target Audience

The 25th Annual Conference of the International Society for Quality of Life Research provides a multidisciplinary forum for clinicians, outcomes researchers, surgeons, psychologists, psychometricians, nurses, new investigators, patient partners and other medical professionals focused on promotion of high quality research in the science of health-related quality of life (HRQOL) measurement and patient-reported outcomes (PRO) to identify effective interventions, enhance the quality of health care and promote the health of populations. ISOQOL provides the premiere opportunity for those in HRQOL and outcomes research to connect and network.

Session Types

The annual conference offers attendees educational opportunities in a variety of formats. The following descriptions can help attendees understand the features of each session type and select the type of instruction best suited to their educational needs.

Plenary Sessions

Plenary sessions are scheduled on Thursday, Friday and Saturday. These sessions are the premiere educational sessions of the Scientific Program. Invited speakers will present on topics of interest to the overall meeting audience in a didactic or panel debate format. Admission to these sessions is by name badge.

Symposium Sessions

Symposia are 90 minute didactic or panel presentations held on Friday and Saturday. Presenters will examine important issues from a variety of different perspectives. Presentations and debate among presenters will address alternative solutions, interpretations or points-of-view on an identified body of knowledge within the advertised topic area or theme. Symposia are selected based on peer-reviewed abstract submissions. Admission to these sessions is by name badge.

Workshops

Workshops are held during the pre-conference on Wednesday. These four-hour sessions feature numerous presenters focused on a specific topic. Workshops are selected based on peer-reviewed proposal submissions. Admission to workshops is by paid ticket only and seating is limited.

Intro to Patient-Reported Outcomes (IPRO) Course

Introduction to Quality of Life and Patient Reported Outcomes Theory, Measurement and Applications

Collecting and acting upon Patient-Reported Outcomes (PROs) is one of the cornerstones of patient centered care. Choosing the right set of PROs can be challenging as there are many options, each with advantages and disadvantages.

This one day, intensive and interactive educational course offers a curriculum that will provide a basic level introduction to the why and how of using PROs in research. Attendees will be given the opportunity to apply their learning throughout the course. This training is aimed at health professionals; medical scientists who are not experts in the use of PROs; consultants; pharmaceutical and medical device representatives; new investigators and research students; policymakers; and other associations and individuals who are interested in acquiring familiarity with the terms and methods of research on PROs.

Intro to PCOR for Pharma/Biotech (IPCOR-Pharma Course)

Introduction to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry: Using PCOR to Inform Decision Making for Regulators, Payers, Prescribers and Patients

PCOR is crucial to successful product development in the pharmaceutical/biotechnology industry. PCOR scientists seeking to pursue a career aligned with this industry should understand the product development process, the product lifecycle, the scientific communication process and interactions with key industry stakeholders – both internal and external (i.e. regulators and payers).

This one-day, intensive and interactive educational course offers a curriculum that will provide an introduction to the application of PCOR research specific to the pharma/biotech industry. It will provide attendees with the opportunity to make informed decisions and advance their career with fundamental knowledge of the pharma/biotech industry. Case studies will engage participants and give them a chance to test their new knowledge.

Industry Special Interest Group (I-SIG) Symposium

This symposium is held on Wednesday and focuses on specific topics with various viewpoints expressed by a panel of experts. This is an invited symposium and has not been peer reviewed.

General Conference Information

Roundtables

Roundtables are informal meetings, with up to nine (9) participants, for networking and discussing mutual interests in a specific work or field. These are invited sessions and have not been peer reviewed. Admission to roundtables is by paid ticket only. Seating per table is limited.

Oral Sessions

Oral sessions are offered on Thursday, Friday and Saturday and last 90 minutes. They are based on peer-reviewed abstracts clustered around common themes and presented via oral presentations. Each presentation is approximately 13 minutes in length (10 minute presentation followed by three minutes of questions and answers from the audience). Admission to these sessions is by name badge.

Poster Sessions

Poster sessions are offered on Thursday, Friday and Saturday and last 30-35 minutes in length. They feature presentations of peer-reviewed abstracts in thematic groupings. Poster sessions allow abstract authors to discuss their research with interested colleagues in an informal setting. These sessions are a great way to see the latest research in the field while socializing with colleagues. Admission to the Poster Hall is by name badge.

- Guidelines**
 Posters are allocated vertical space that is 1 m (39 inches) wide by 2.25 m (88 inches) high. Posters must not exceed the allocated space.
- Poster Numbers**
 All posters are assigned a poster number corresponding to the poster's listing in the final program. Odd numbered posters will be presented in the morning during the daily Session I, and even numbered posters will be presented in the afternoon during the daily Session II. Posters should be displayed for the full day in which they are assigned.
- Set up and Removal**
 Presenters are responsible for setting up and removing posters during the assigned set up and removal times. Push pins or appropriate fasteners are provided. All posters are assigned a presentation day and time. Posters should be displayed for the full day in which they are assigned. A detailed schedule of set up and removal times is listed below.

Posters that are not removed by the end of the scheduled removal time will be discarded.

	Thursday 25 October	Friday 26 October	Saturday 27 October
Poster Set Up <i>All Posters</i>	7:00 - 10:00 am	7:00 - 10:00 am	7:00 - 9:30 am
Session 1 Presentations Odd numbers	10:10 - 10:45 am	10:35 - 11:10 am	9:45 - 10:15 am
Session 2 Presentations Even numbers	3:25 - 4:00 pm	3:35 - 4:10 pm	3:15 - 3:45 pm
Poster Removal <i>All Posters</i>	4:30 - 6:30 pm	4:15 - 5:45 pm	3:45 - 5:15 pm

- Poster Hall Hours**

All poster presentations will take place in the Lansdowne Room. The Poster Hall will be open daily from 7:00 am – 5:00 pm from Thursday, 25 October – Saturday, 27 October.

Registration Desk

ISOQOL accepts MasterCard, Visa, American Express and Discover credit cards. Cash transactions may be made in Euros. Payment by check is accepted so long as the check is in US dollars and drawn on a US bank account.

Registration Desk Hours

Wednesday, 24 October: 7:00 am – 7:00 pm
 Thursday, 25 October: 7:00 am – 6:30 pm
 Friday, 26 October: 7:00 am – 5:45 pm
 Saturday, 27 October: 7:00 am – 5:20 pm

Lunch

The conference registration fee includes a buffet lunch on Thursday, Friday and Saturday. Lunch will be served in the Sussex Restaurant on the ground floor. Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. Entry into the buffet is by name badge.

Lunch Shifts

Thursday, 25 October	12:05 pm - 12:50 pm 1:00 pm - 1:45 pm
Friday, 26 October	12:30 pm - 1:15 pm 1:15 pm - 2:00 pm
Saturday, 27 October	12:30 pm - 1:15 pm 1:15 pm - 2:00 pm

General Conference Information

Ticketed Events

A ticket is required for the education courses, workshops, roundtables, and the closing dinner. Tickets are available at the Registration Desk while supplies last, or through Friday, 26 October, at 11:00 am.

Cancellation Policy

ISOQOL reserves the right to cancel any event due to lack of enrollment or other factors. In the event of a cancellation, registered participants will be notified by e-mail and will have the option to exchange their ticket for an available alternative, or to receive a complete refund.

Certificates of Attendance

Certificates of Attendance will be emailed to all attendees the week following the conclusion of the conference.

Certificates of Presentation

Certificates of Presentation are available for presenters who requested a certificate on the registration form. Oral presentation certificates are distributed at the conclusion of each oral session by the session chair. Poster certificates can be picked up at the registration desk.

If you did not request a certificate in advance, you can request a certificate by sending an e-mail to the ISOQOL Office at info@isoqol.org. Certificates requested during the conference will be distributed electronically following the conclusion of the conference.

Evaluations

Please take time to complete the Annual Conference evaluation that will be distributed electronically immediately following the conclusion of the conference. Your input and comments are essential in planning future educational events.

Workshop attendees are sent evaluations via email upon the conclusion of the workshops. Responses to these evaluations are requested no later than 31 October.

Photography Disclaimer

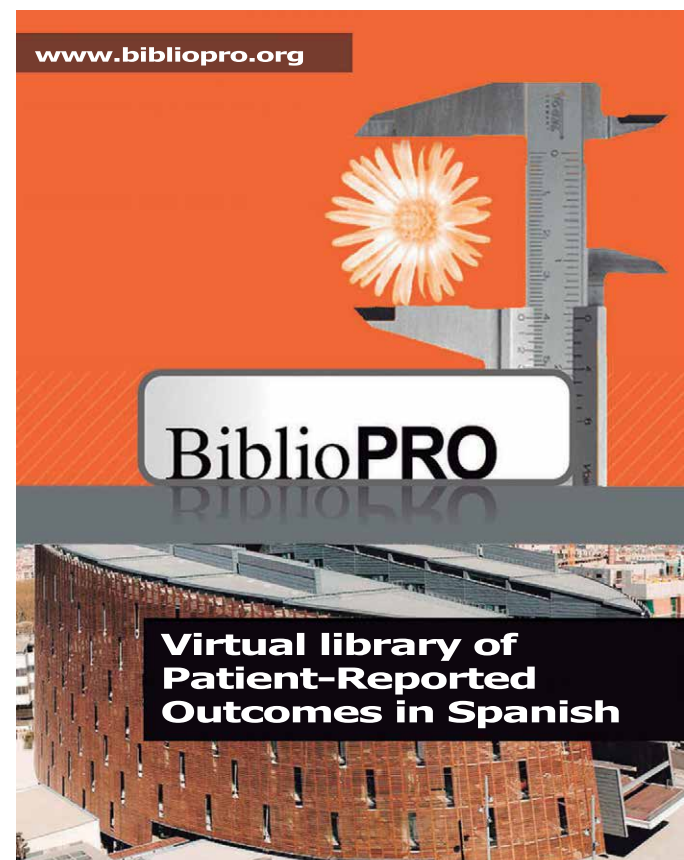
By registering for the ISOQOL Annual Conference, you give consent to be photographed by ISOQOL staff for purposes of advertising and public display.

Session Recording

Session content is copyright-protected by ISOQOL. Recording of any session without the consent of ISOQOL is prohibited. Any recording done with consent of ISOQOL is for personal use only and cannot be reproduced or distributed.

Final Program

The 25th Annual Conference program will be archived online at <http://www.isoqol.org/education-events/past-events>.



About ISOQOL

Dedicated to the promotion of excellence in the science of health-related quality of life.

International Society for Quality of Life Research (ISOQOL) established in 1993, is a non-profit society 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 provides the premiere opportunity for those in the quality of life research field to connect and network.

Quality of life has become a prominent subject in philosophy, social science, clinical medicine, health services, and outcomes research. With over 600 members representing 43 countries, ISOQOL is an international society with activities focused on promotion of high quality research in the science of health-related quality of life (HRQOL) measurement and patient-reported outcomes (PRO).

Programs and Projects

Education Programs

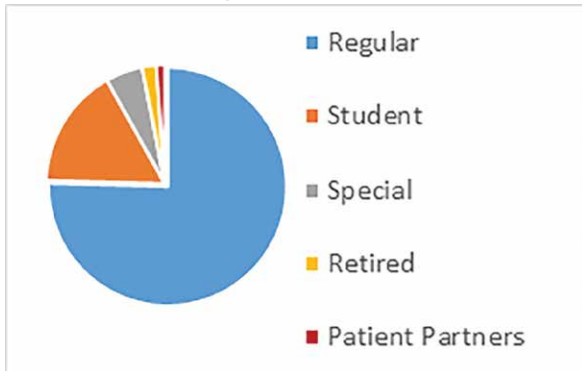
- Annual Conference
- Measuring What Matters Symposium
- Intro to Patient-Reported Outcomes (IPRO Course) – Introduction to Quality of Life and Patient-Reported Outcomes: Theory, Measurement, and Applications
- Intro to Patient-Centered Outcomes Research (PCOR) for the Pharma/Biotech Industry (IPCOR-Pharma Course)
- Mentor/Mentee Program
- Special Interest Groups (SIGs)

Publications

- *Journal of Patient Reported Outcomes (JPRO)*
- *Quality of Life Research Journal (QLR)*
- *ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement (English & Portuguese)*
- *User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice (2015)*
- *Companion Guide to the ISOQOL User's Guide (2018)*
- *ISOQOL's comment on EMA draft reflection paper on the use of patient-reported outcome (PRO) measures in oncology studies (2015)*
- *ISOQOL Recommends Minimum Standards for Patient-Reported Outcome Measures Used in Patient-Centered Outcomes and Comparative Effectiveness Research (2013)*
- *Patient-Reported Outcomes in Randomized Clinical Trials (2012/2013)*
- *Using Patient-Reported Outcome Measures to Improve Clinical Practice (2012)*

About ISOQOL

ISOQOL Membership



Benefits of Membership

As a member you belong to a global community of researchers, clinicians, industry professionals, government leaders, patients, and other professionals who share your passion for quality of life research.

ISOQOL membership provides access to a collection of tools, resources, content, development opportunities, and a vibrant community of peers.



Tools and Resources

- Free Access to the online subscription to the *Quality of Life Research Journal*
- Discounted print subscription to *Quality of Life Research*
- Access to ISOQOL's official open access journal, *Journal of Patient-Reported Outcomes*
- Updates from ISOQOL's newsletter – *Quality of Life Quarterly*
- Discounted access to PRO and QoL Instruments Database



Grow

- Online education with reduced rates
- Discounted Annual Conference registration
- Discounted Measuring What Matters registration
- Reduced rate for Intro to Patient-Reported Outcomes (IPRO) Course
- Reduced rate for Intro to PCOR for Pharma/Biotech (IPCOR-Pharma Course)



Connect

- Serve in leadership roles and sit on ISOQOL Committees and Initiatives
- Participation in Special Interest Groups (SIGs) with access to Teamwork
- Access to ISOQOL membership directory

ISOQOL Leadership

Executive Committee



President
Jose M. Valderas, MD,
MPH, PhD
United Kingdom



Secretary-Treasurer
Joan Branin, PhD
United States



Past President
Claire Snyder, PhD
United States

Board of Directors



Susan Bartlett, PhD
Canada



Mogens Groenvold, MD,
PhD
Denmark



Anne Klassen, DPhil
United States



Ida Korfage, PhD
Netherlands



Josephine Norquist, MS
United States



Antoine Regnault, PhD
France



Diana Rofail, PhD, CPsychol
United Kingdom



Kevin Weinfurt, PhD
United States



Zoe Winters, DPhil, FRCS,
FCS, MD
United Kingdom

Co-Editors of Journal of Patient-Reported Outcomes



David Feeny, PhD
Canada



Dennis Revicki, PhD
United States

Co-Editors of Quality of Life Research Journal



Jan. R. Boehnke
United Kingdom



Frans Jeroen Oort, PhD
Netherlands

ISOQOL Office Staff



Executive Director
Colleen Pedersen



Meetings Manager
Marina Shawd



**Communications and
Membership Manager**
Samantha Walker



Program Coordinator
Charise Maldonado



**Membership and
Program Coordinator**
Caitlin Willenbrink

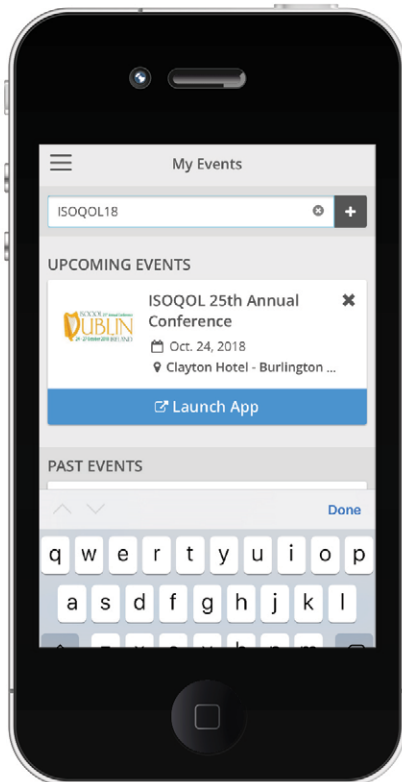


KEEP THE CONFERENCE PROGRAM IN YOUR POCKET

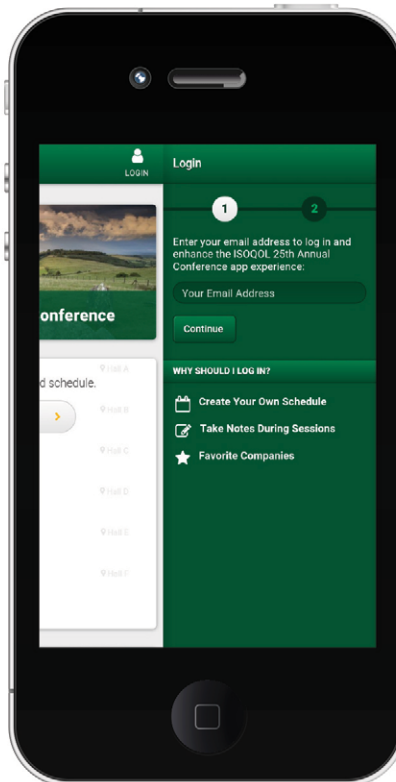


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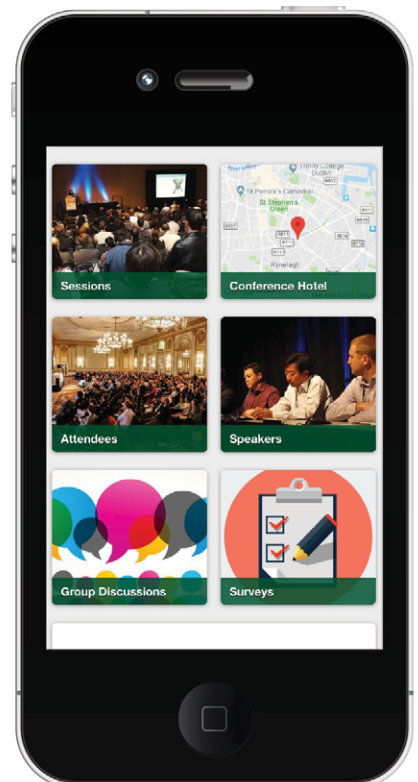
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Enter code **ISOQOL18** to access the 25th Annual Conference details.



Create an account to save conference sessions to your own personal schedule.



Message other attendees and speakers, view upcoming sessions, and more!

Committees

Advisory Council of Past Presidents

Bryce Reeve, PhD, US — Co-chair
Galina Velikova, MD, PhD, UK — Co-chair

2013-2015 Galina Velikova, MD, United Kingdom
2011-2013 Bryce B. Reeve, PhD, United States
2010-2011 Carol M. Moinpour, PhD, United States
2009-2010 Diane L. Fairclough, DrPH, United States
2008-2009 Neil K. Aaronson, PhD, Netherlands
2006-2007 Madeleine T. King, PhD, Australia
2005-2006 Peter Fayers, PhD, United Kingdom
2004-2005 David Feeny, PhD, Canada
2003-2004 Albert W. Wu, MD, MPH, United States
2002-2003 Mirjam AG Sprangers, PhD, Netherlands
2001-2002 David Osoba, MD, Canada
2000-2001 Ivan Barofsky, PhD, United States
1998-2000 Sharon Wood-Dauphinee, PhD, Canada
1996-1998 Monika Bullinger, PhD, Germany
1994-1996 Robert Kaplan, PhD, United States
1993-1994 Donald L. Patrick, PhD, MSPH, United States

25th Annual Conference Scientific Program Committee

Diana Rofail, PhD, CPsychol, United Kingdom – Co-chair
Joanne Greenhalgh, PhD, United Kingdom – Co-chair
Skye Barbic, PhD, Canada – Symposium Chair
Karl McEvoy, PhD, United Kingdom – Local Representative

Audit Committee

Jose M. Valderas, MD, MPH, PhD, United Kingdom
Joan Branin, PhD, United States
Claire Snyder, PhD, United States

Education Committee

William Lenderking, PhD, United States
Skye Barbic, PhD, Canada

Intro to Patient-Reported Outcomes (IPRO) Course

Nancy Mayo, PhD, Canada
Heather Gelhorn, PhD, United States

Mentor/Mentee

Maria-Jose Santana, PhD, Canada
Juliana Bredemeier, United States

Webinar

Thomas Willgoss, PhD, United Kingdom
Claudia Rutherford, PhD, Australia

Workshop

Rick Sawatzky, RN, Canada
Elizabeth Unni, PhD, United States

Nominations Committee

Claire Snyder, PhD, US — Chair
Ida Korfage, PhD, Netherlands
Josephine Norquist, MS, United States
Kevin Weinfurt, PhD, United States

Standards & Best Practices Committee

Susan Bartlett, PhD, Canada — Past Chair
Melanie Calvert, PhD, United Kingdom — Chair

Quality of Life Quarterly Newsletter Editor

Ana Popielnicki, BA, United States

Judging Panels

Scholarships

(New Investigator/Student, Developing Country and Patient Research Partner)

Sam Salek, PhD, United Kingdom
Gloria Juarez, PhD, United States
Marcelo P. Fleck, MD, PhD, Brazil
Ana Maria Rodriguez, PhD, Spain
Laura Pinheiro, PhD, United States

Emerging Leader Award Committee

Madeleine King, PhD, Australia
Carol Moinpour, PhD, United States
Ida Korfage, PhD, Netherlands
Anne Klassen, DPhil, Canada
Skye Barbic, PhD, Canada

Special Interest Groups (SIGs)

Australia

Ljoudmila Busija, PhD, Australia
Claudia Rutherford, PhD, Australia
Rasa Ruseckaite, Australia
Rebecca Mercieca-Bebber, Australia

Canada PRO

Sara Ahmed, PhD, Canada
Susan Bartlett, PhD, Canada

Child Health

Jeanne Landgraf, MA, United States
Anne-Catherine Haller, Dipl.Psych, Germany
Nalin Payakachat, PhD, United States

Chinese PRO

Daniel Fong, PhD, Hong Kong
Ji-qian Fang, PhD, China

Health Preference Research

Richard L. Skolasky, ScD, United States
Zoe Winters, DPhil, United Kingdom

Ibero American

Monica Avila, Bpharm, Spain

Industry

Emuella Flood, United States
Paivi Miskala, MSPH, PhD, United States

Mixed Methods

Thomas Willgoss, PhD, United Kingdom
Skye Barbic, PhD, United States

New Investigator

Manraj Kaur, PhD, Canada
Canhua Xiao, PhD, United States

Patient Engagement

Sam Salek, PhD, United Kingdom
Kirstie Haywood, DPhil, United Kingdom

Psychometrics

Stacie Hudgens, MA (AbD), United States
RJ Wirth, United States
Frances Yang, PhD, United States

QOL Clinical Practice

Louise Newton, MSc, United Kingdom
Lotte Haverman, PhD, Netherlands
Kathryn Flynn, PhD, United States

Response Shift

Veronique Sebillle, ScD, PhD, France
Tolulope Sajobi, PhD, Canada

Translation & Cultural Adaptation

Sonya Eremenco, MA, United States
Benjamin Arnold, MA, United States
Ana Popielnicki, United States
Dagmara Kuliś, MA, Belgium

United Kingdom and Ireland

Elizabeth Gibbons, MSc, United Kingdom
Anju Keetharuth, PhD, United Kingdom

Awards and Scholarships

President's Award

The President's Award is awarded to an individual who has advanced HRQOL research and has made outstanding contributions to the Society 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.

Congratulations to the 2018 President's Award recipient:

Andrew Bottomley, PhD presented by Jose M. Valderas, MD, MPH, PhD

- 2017 Nancy E. Mayo, PhD *presented by Claire Snyder, PhD*
- 2016 Carolyn E. Schwartz, ScD *presented by Claire Snyder, PhD*
- 2015 Carol M. Moinpour, PhD *presented by Galina Velikova, MD*
- 2014 Mirjam AG Sprangers, PhD *presented by Galina Velikova, MD*
- 2013 Peter Fayers, PhD *presented by Bryce B. Reeve, PhD*
- 2012 Diane Fairclough, DrPH *presented by Bryce B. Reeve, PhD*
- 2011 Carolyn C. Gotay, PhD *presented by Carol M. Moinpour, PhD*
- 2010 David Feeny, PhD *presented by Diane Fairclough DrPH*
- 2009 Ronald D. Hays, PhD *presented by Neil Aaronson, PhD*
- 2008 David Cella, PhD *presented by Donna Lamping, PhD*
- 2007 Dennis Revicki, PhD *presented by Madeleine T. King, PhD*
- 2006 David Osoba, MD *presented by Peter Fayers, PhD*
- 2005 Neil Aaronson, PhD *presented by David Feeny, PhD*
- 2004 Robert Kaplan, PhD *presented by Albert Wu, MD MPH*
- 2003 John E. Ware, PhD *presented by Mirjam AG Sprangers, PhD*
- 2002 George Torrance, PhD *presented by David Osoba, MD*
- 2001 Donald Patrick, PhD MSPH *presented by Ivan Barofsky, PhD*

Emerging Leader Award – In Honor of Donna Lamping

The Emerging Leader Award was established in 2011 to honor and commemorate past-President Donna Lamping's contribution to the leadership of the Society. This is awarded to an ISOQOL member who has shown exceptional leadership skills and potential.

Congratulations to the 2018 Emerging Leader Award recipient:

Tom Willgoss, PhD, MSc, BA

- 2017 Skye P. Barbic, PhD, OT
- 2015 Bellinda L. King-Kallimanis, PhD
- 2014 Antonia V. Bennett, PhD
- 2013 Roxanne Jensen, PhD
- 2012 Melanie Calvert, PhD

ISOQOL Travel Scholarship Fundraiser Donate Today



Help ISOQOL increase the number of Travel Scholarships awarded next year!

ISOQOL awards Travel Scholarships for the Annual Conference each year to:

- Patient Research Partners
- Members from Developing Countries
- Students and New Investigators

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Corporate Scholarship Sponsor

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www.isoqol.org/movetheplane-fundraiser

Awards and Scholarships

Outstanding Article of the Year Awards

This award recognizes the best articles dedicated to HRQOL and PRO research published in the **Quality of Life Research** journal and the **Journal of Patient Reported Outcomes** during the previous calendar year. The award recognizes the authors for significant intellectual contributions that promise to advance the state of the art in HRQOL research methods or theory.

Congratulations to the Outstanding Articles of the Year:

2017 Quality of Life Research Recipient

Ratcliffe, J., Lancsar, E., Flint, T., Kaambwa, B., Walker, R., Lewin, G., Luszcz, M., & Cameron, I. D. (2017). Does one size fit all? Assessing the preferences of older and younger people for attributes of quality of life. *Quality of Life Research*, 26(2), 299-309. doi:<https://doi.org/10.1007/s11136-016-1391-6>

2017 Journal of Patient Reported Outcomes Recipient

Humphrey, L., Wilgoss, T., Trigg, A., Meysner, S., Kane, M., Dickinson, S., & Kitchen, H. (2017). A comparison of three methods to generate a conceptual understanding of a disease based on the patients' perspective. *Journal of Patient-Reported Outcomes*, 1(9). doi:<https://doi.org/10.1186/s41687-017-0013-6>

2017 Finalists for Quality of Life Research

Moseholm, E., Rydahl-Hansen, S., Lindhardt, B. Ø., & Fetters, M. D. (2017). Health-related quality of life in patients with serious non-specific symptoms undergoing evaluation for possible cancer and their experience during the process: A mixed methods study. *Quality of Life Research*, 26(4), 993-1006. doi:<https://doi.org/10.1007/s11136-016-1423-2>

Emerson, S. D., Guhn, M., & Gadermann, A. M. (2017). Measurement invariance of the Satisfaction with Life Scale: Reviewing three decades of research. *Quality of Life Research*, 26(9), 2251-2264. doi:<https://doi.org/10.1007/s11136-017-1552-2>

2017 Finalists for Journal of Patient Reported Outcomes

Hays, R. D., Schalet, B. D., Spritzer, K. L., & Cella, D. (2017). Two-item PROMIS® global physical and mental health scales. *Journal of Patient-Reported Outcomes*, 1(2). doi:<https://doi.org/10.1186/s41687-017-0003-8>

Rodday, A. M., Graham, R. J., Weidner, R. A., Rothrock, N. E., Dewalt, D. A., & Parsons, S. K. (2017). Leveraging pediatric PROMIS item banks to assess physical functioning in children at risk for severe functional loss. *Journal of Patient-Reported Outcomes*, 1(10). doi:<https://doi.org/10.1186/s41687-017-0011-8>

New Investigator and Student Presentation Awards

These 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. Finalists are selected based upon the scores received during the abstract review process. Student and New Investigator Poster Award Finalists are invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference.

Congratulations to the 2018 New Investigator and Student Presentation Finalists

New Investigator Oral Presentation

Andrew Trigg, MSc, Adelphi Values, Manchester, United Kingdom

101.1: *Triangulating estimates of meaningful change or difference in patient-reported outcomes: application of a correlation-based weighting procedure*

Derek Kyte, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom
203.3: *Systematic evaluation of patient-reported outcome (PRO) protocol content and reporting in cancer clinical trials: the EPIC study*

Madeline Pe, PhD, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium

203.4: *Improving standards of patient reported outcomes analysis: developing a consensus taxonomy of key research objectives – a SISAQOL initiative*

Awards and Scholarships

New Investigator Poster Presentation

John Peipert, PhD, Northwestern University, Chicago, IL, United States

2003: Measurement Invariance between Black and White Dialysis Patients and Normative Scores for the General Dialysis Population in the United States on The Kidney Disease Quality of Life 36-item Short-form Survey (KDQOL-36)

Philip Griffiths, PhD, Clinical Outcomes Solutions, Folkestone, United Kingdom

2005: Psychometric Properties in the Face of Missing Data - A Simulation Study Assessing the Effect of Missing Data on Test-Retest Reliability in Diary Studies

Mark Ferro, PhD, University of Waterloo, Waterloo, Ontario, Canada

2007: Effects of Parental Psychopathology on Reports of Child Health-related Quality of Life

Student Oral Presentation

Lisa McGarrigle, PhD, DGI Clinical, Halifax, Nova Scotia, Canada

104.2: Exploring the responsiveness of Goal Attainment Scaling (GAS) in relation to number of goals set in a sample of patients with Alzheimer's Disease

Joshua Biber, MS, MBA, University of Utah Health, Salt Lake City, UT, United States

107.1: Mapping PROMIS Physical Function Scores to Functional Ability

Lene Kongsgaard Nielsen, MD, PhD Candidate, Quality of Life Research Center, Department of Hematology, Odense University Hospital and OPEN, Odense Patient data Explorative Network, Odense University Hospital, Odense, Denmark

208.2: Reason for not completing quality of life questionnaires in multiple myeloma patients

Student Poster Presentation

Jussi Repo, MD, PhD, Department of Surgery, Central Finland Central Hospital, Jyväskylä, Finland;

2004: Psychometric properties of the SRS-30 questionnaire among adult spinal disease patients: a Rasch analytic approach

Lois F. van de Water, MSc, Academic Medical Center Amsterdam, Amsterdam, Netherlands;

2006: Communicating treatment risks and benefits to cancer patients: a systematic review of different verbal and visual communication methods.

Tamara Crittenden, BAppSc (Hons), College of Medicine & Public Health, Flinders University, Bedford Park, Adelaide, Australia

2008: Normative data for the BREAST-Q Reduction module in an Australian population

Outstanding Poster Abstract Awards

The top six (6) posters that scored the highest during the abstract review process will be recognized with a ribbon posted on their poster board and are invited to display their poster throughout the entire conference and present in front of a panel of judges and the attendees at the Annual Conference. Each Outstanding Poster Abstract Award Finalist will be highlighted in the Final Program and will be acknowledged on a PowerPoint slide at the Awards Presentation during the ISOQOL Members Business Meeting. At this time, the winner will be announced and presented with a framed certificate.

Congratulations to the 2018 Outstanding Poster Award Finalists:

Sara Fernandes, PhD student, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France

1003: The Patient-Reported Experience Measure for Improving Quality of care in Mental health (PREMIUM) project in France: domain mapping process and item selection

Irina Ghislain, MSc, EORTC, Brussels, Belgium; Corneel Coens, MSc, EORTC, Brussels, Belgium

1004: Quality of life as an outcome in EORTC clinical trials: 15 years of clinical trial research

Amaia Bilbao, PhD, Research Unit, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain

1005: Total hip arthroplasty: long-term health related quality of life outcomes

Elizabeth Cox, MD, PhD, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States

1006: Reliability and validity of PROMIS Pediatric Family Relationships short form in children with chronic disease

Awards and Scholarships

Deborah Miller, PhD, LISW-S, Cleveland Clinic Mellen Center, Cleveland, OH, United States

1007: Association between Neuro-QoL Scale Scores and Employment Status in MS PATHS (Multiple Sclerosis Partners Advancing Technology and Health Solutions) Patients.

Borghild Løyland, Associate Professor, Oslo Metropolitan university, Oslo, Norway

1008: Down and out? Work and welfare trajectories among a cohort of Norwegian long-term social assistance recipients with complex health problems and low quality of life.

Scholarships

Developing Country Scholarship

Meng Wang, Canada

Yangjun Liu, PhD Student, Sweden

New Investigator and Student Scholarship

Sana Ishaque, PhD Candidate, Australia

Nathan Pearson, MSc, BSc (Hons), United Kingdom

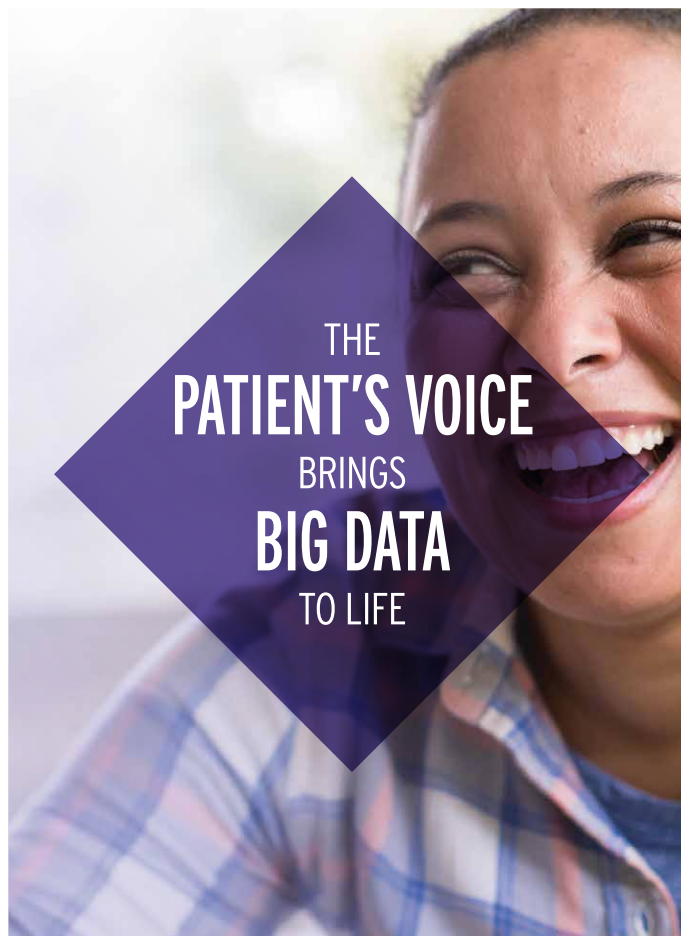
Hannah Penton, United Kingdom

Patient Engagement Scholarship

Jaqueline Jones, United Kingdom

Mary Stanbury, United Kingdom

Sandra Zelinsky, Canada



The efforts to improve health outcomes today are numerous and expansive. But these best intentions often miss the patient's perspective about his or her own care. As a health services and innovation company, we believe capturing reliable, practical and scientifically valid information on the patient's health and well-being is critical to evaluating outcomes and advancing health policy. We're doing more than logging data points. Our tools take us straight to the source — the patients themselves. When we amplify the patient's voice, we can better hear the answer to, "What does health care mean to you?"

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Thank You to the 2018 Abstract Reviewers

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Alessandra Vanoli, BSc, MSc
Allison Martin Nguyen
Amanda Spraggs-Hughes
Amit Bodhani
Ana Popielnicki, BA
Andrew Bottomley, PhD
Andrew Palsgrove, BA
Angela Stover, PhD
Anju Keetharuth
Ann Hartry, PhD
Anne-Marie Russell
Antoine Regnault, PhD
Asha Hareendran, PhD
Ayse Kuspinar, BSc(PT), MSc, PhD
Barbara Gandek, PhD
Bhumi Trivedi
Brittany Lapin, PhD, MPH
Canhua Xiao, PhD
Caroline Terwee, PhD
Carolyn Schwartz, ScD
Christine Blome, PhD
Cindy Nowinski, MD, PhD
Cynthia Girman, DrPH, FISPE
Cynthia Gross, PhD
Cynthia Grossman, PhD
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Daniel Van Leeuwen, Opa, RN, MPH
David Andrae, PhD
Dennis Revicki, PhD
Diana Rofail, PhD, CPsychol
Diane Fairclough, DrPH
Dianna Wuagneux, PhD
Efsthios Zikos, MS, MA
Elisavet Moschopoulou, BSc, MSc
Elizabeth Bush, MHS
Elizabeth Gibbons, MSc
Elizabeth Unni, PhD
Elizabeth Yohe-Moore, MPH
Emre Yucel, PhD
Eva Bitzer, MD, MPH
Felix Fischer, PhD
Frances Yang, PhD
Gloria Juarez, PhD, RN, MSN
Guannan Bai, MSc
Heather Gelhorn, PhD
Helen McTaggart-Cowan, PhD
Henriette Markwart
Holger Muehlan, PhD
Hongmei Yu, PhD
I-Chan Huang, PhD
James Shaw, PhD, MPH
Jan Boehnke
Jasmine Kamboj, MD
Jayanti Ray, PhD
Jessica Roydhouse, PhD
Joanne Greenhalgh, PhD
Joel Gagnier, ND, MSc, PhD
Juliana Bredemeier, Psychologist, PhD
Julie Panepinto, MD, MSPH
Jussi Repo, MD
Katarzyna Wac, PhD
Kathryn Flynn, PhD
Kedar Mate
Kevin Weinfurt, PhD
Kim Cocks, PhD
Kyle Kemp, MSc
Lari Wenzel, PhD
Lars Eriksson, PhD
Lauren Lent, DHA, MS
Ligia Chavez, PhD
Linda Nelsen, MHS
Lionne Venderbos, PhD
Lizete Malagoni
Lori Frank, PhD
Lotte Haverman, PhD
Majid Omidikhankahdani
Manraj Kaur, PT, MSc, PhD(c)
Marcelo Fleck, MD, PhD
Martha Shumway, PhD
Melanie Hawkins, BA, BHSc, MPH
Melissa Thong
Melissa Tinsley
Michelle White, PhD
Montserrat Ferrer, MD, PhD, MPU
Morten Petersen, MSCi
Motolani Ogunsanya, BPharm, MS, PhD
Nadia Corsini
Nalin Payakachat, BPharm, MS, PhD
Namita Joshi, PhD
Nancy Young, PhD
Naomi Knoble, PhD
Nathan Pearson, MSc, BSc (Hons)
Niels Wedderkopp, MD, PhD
Olalekan Lee Aiyegbusi, MBChB
Oluwagbohunmi Awosoga, PhD, MBA
Patricia Koochaki, PhD
Pedro Lopez-Ferreira, PhD
Peter Williams, FRCA, MSc, FFPMRCA
Rachel Ballinger, PhD
Rahul Dhanda
Rasa Ruseckaite
Raymond Baser, MS
Rebecca Mercieca-Bebber
Richard Skolasky, ScD
Rick Sawatzky, PhD, RN
Ronald Hays, PhD
Roxanne Jensen, PhD
Samantha Anthony, PhD, MSW
Sandra Mitchell, PhD, CRNP, AOCN
Sara Pérez
Sarah Donelson, MA
Sean Mikles, MPH
Shanshan Qin, PhD
Shreekant Parasuraman, PhD
Silja Voolma
Skye Barbic, PhD, OT
Somali Burgess, PhD
Stacie Hudgens, MA (AbD)
Susan Yount, PhD
Tempei Miyaji
Teresa Tsui, BSc(Hon), MSc
Teresa Young, BSc
Theresa Coles, PhD
Thomas Atkinson, PhD
Thor Gamst-Klaussen
Timothy Poepsel, PhD
Tomoaki Kimura, PhD
Tracey Young, PhD, MSc, BSc, CStat
Tzu-Hua Ho
Vera Lucia Santos, PhD
Virgina Visconde-Brasil
Wenjie Duan, PhD
William Lenderking, PhD
Yara Asi, PhD

Plenary Speakers

Plenary 1: Digital self-tracking to support patient self-management

Thursday, 25 October 2018; 8:30 am - 10:00 am



Bruce Hellman, MBA

uMotif
London, United Kingdom

Bruce Hellman is CEO and Co-Founder of uMotif, the leading platform to capture patient-generated data through tools patients love to use. Bruce has been recognized as one of Computer Weekly's UKtech50 Rising Stars, won the Cisco BIG and AXA PPP Healthtech & You awards, and was nominated by Real Business magazine as one of the '30 to watch in mobile'. Bruce began his career in the Civil Service Fast Stream, working in the Department for Culture, Media before further public-service delivery experience at Serco. Following an Executive MBA from Imperial College Business School, Bruce founded uMotif. Bruce is a three-time Ironman finisher.



Elizabeth Murray, FRCGP FRCP (Edin) PhD

University College London
London, United Kingdom

Elizabeth Murray is a GP, Professor of eHealth and Primary Care, and Head of the Research Department of Primary Care and Population Health at University College London, UK. Following a US Harkness Fellowship in Health Care Policy 2001 – 02 she was awarded a Career Scientist Award from the UK Department of Health. Her research has three foci: developing and evaluating digital health interventions; implementation of digital health into routine care; and the impact of digital health on healthcare professional – patient interactions. Elizabeth's grant income for the past 5 years is around £16 million and she has over 150 publications.



Emma Rich, BSc, PhD

University of Bath
Bath, United Kingdom

Dr Emma Rich is a Reader/Associate Professor in Department for Health, University of Bath. Her research examines sport, physical activity and health education from a critical socio-cultural perspective. She is leading a research project funded by the Wellcome Trust 'The Digital Health Generation: The impact of 'healthy lifestyle' technologies on young people's learning, identities and health'. She has published 3 books: Education, Disordered eating and Obesity Discourse: Fat Fabrications (Routledge) the Medicalization of Cyberspace (Routledge) and Debating Obesity: Critical Perspectives (Palgrave Macmillan). Her latest book with Lee Monaghan and Andrea Bombak is 'Rethinking Obesity: Critical perspectives on research, policy and practice'.

Plenary 2: Cutting Edge Research

Thursday 25, October 2018; 10:50 am - 12:00 pm

Sponsored By: Vector Psychometric Group



Yuelin Li, PhD

Memorial Sloan Kettering Cancer Center
New York, NY, United States

Dr. Li is a behavioral statistician with a joint appointment in the Department of Psychiatry & Behavioral Sciences and the Department of Epidemiology and Biostatistics. His current research focuses on analyzing PRO data using Machine Learning analytics, including Latent Dirichlet Allocation (LDA) and Bayesian Nonparametric (BNP) methods. These methods offer new possibilities in PRO data analysis. For example, LDA can quantify how cancer patients' goals and priorities change over time using free-text transcripts of what patients say matter the most to them personally. Patients' goals can now be incorporated to enhance conventional data from fixed-length QOL measures. Dr. Li also works on making these revolutionary ideas accessible to behavioral scientists, in his tutorials on Bayesian psychometric methods (PMID: 29424559, 22362655, 27193366) and BNP mixture modeling (forthcoming).

Plenary Speakers



Kyle Kemp, MSc, PhD Candidate

University of Calgary,
Calgary, Alberta, Canada

Kyle Kemp is a PhD candidate in the Department of Community Health Sciences at the University of Calgary. His research explores the relationships between the experiences of patients in Canadian hospitals, quality of life, and outcomes. Kyle has extensive experience using large administrative data sets, and has a keen interest in the use of dynamic data visualizations for reporting and quality improvement purposes. To date, he has authored 25 peer-reviewed manuscripts, and has received awards from the Canadian Institutes of Health Research, the Canadian Association for Health Services and Policy Research, Alberta Innovates, and the Nova Scotia Health Research Foundation.



I-Chan Huang, PhD

St. Jude Children's Research Hospital
Memphis, TN, United States

Dr. I-Chan Huang received his PhD from Johns Hopkins University School of Public Health. His training is in health services and outcomes research with an emphasis on PRO measurement in pediatric populations. Currently, Dr. Huang is an Associate Member/Associate Professor in the Department of Epidemiology and Cancer Control at St. Jude Children's Research Hospital, Tennessee. His research focuses on measuring symptom profiles for pediatric cancer patients and survivors, exploring bio-psycho-social mechanisms of symptom burden, and translating symptom data sciences into clinical interventions. His research has been funded by U.S. National Institutes of Health and National Cancer Institute.



Adrian Levitsky, PhD

Karolinska Institutet
Stockholm, Sweden

Adrian Levitsky holds a competitive Postdoctoral Researcher position at the Division for Innovative Care Research at Karolinska Institutet, at both the Department of Learning, Informatics, Management and Ethics, and the Research Group for Cancer Proteomics Mass Spectrometry, Science for Life Laboratory. In his PhD, he focused on implementing personalized medicine and integrative interventions in rheumatoid arthritis. He is currently investigating complex interactions among biological, social, and behavioral factors through bio-behavioral research: linking patients' first experiences of symptoms with biological data to facilitate earlier diagnosis of lung cancer and add to understanding of how symptoms and bodily sensations are perceived.

Plenary 3: Big data to support research and health care

Friday, 26 October 2018; 9:00 am - 10:30 am

Sponsored By: EORTC



Michael Schull, MD, MS, FRCPC

Institute for Clinical Evaluative Sciences
Toronto, ON, Canada

Michael Schull is President, CEO and Senior Scientist at the Institute for Clinical Evaluative Sciences, and Professor in the Department of Medicine at the University of Toronto. His research focuses on health service utilization, quality of care, health system integration and patient outcomes, and the evaluation of health policy. His studies use administrative health datasets and linkages with clinical data, and he works closely with health system decision and policy makers. Dr. Schull practices as an Emergency Medicine specialist at Sunnybrook Health Sciences Centre in Toronto.



David Stillwell, PhD

University of Cambridge
Cambridge, United Kingdom

Dr. David Stillwell is Lecturer in Big Data Analytics and Quantitative Social Science at Judge Business School in the University of Cambridge. He is also Deputy Director of the Psychometrics Centre. David studies the links between online behaviour and psychology; his research with six million Facebook users found that the computer can predict a user's personality as accurately as their spouse can.

Plenary Speakers



Emma Uprichard
University of Warwick
Warwick, United Kingdom

Emma Uprichard is Reader at the Centre for Interdisciplinary Methodologies, University of Warwick. She has longstanding interests in the methodological challenge of studying complex social systems across time and space for policy planning purposes. She is currently a Fellow of the Alan Turing Institute, a member of The National Statistician's Data Ethics Advisory Committee (NSDEC) and co-editor of the International Journal of Social Research Methodology. She is also co-investigator on CECAN, the 'Centre for the Evaluation of Complexity Across the Nexus', a national research centre funded tasked with developing methods for complex evaluation.

Plenary 4: Generalizability of validity data across diseases and treatment settings: when is enough, enough?

Saturday, 27 October 2018; 11:00 am - 12:30 pm

Sponsored By: Roche



Stefan Cano, PhD, CPsychol, AFBPsS
Modus Outcomes
Letchworth Garden City, United Kingdom

Stefan Cano is Co-Founder and Chief Scientific Officer at Modus Outcomes and co-developer of Q-Portfolio instruments for cosmetic, plastic, reconstructive, and cancer surgery called BREAST-Q, FACE-Q, BODY-Q, and CLEFT-Q. He is an Associate Fellow of the British Psychological Society and has 24 years of experience in patient centered outcomes (PCO) research. Stefan is interested in applying and improving mixed methods psychometric research in clinical studies, with a focus on maximizing the interpretability of PCO instruments. He has published 150+ articles in peer review journals. Stefan previously sat on the ISOQOL Board of Directors and served as co-chair of the 17th Annual Conference in 2010.



David Cella, PhD
Northwestern University
Evanston, IL, United States

Dr. Cella is currently Professor and Chair of the Department of Medical Social Sciences at Northwestern University Feinberg School of Medicine. He also directs the Center for Patient Centered Outcomes Research at Northwestern's Institute for Public Health and Medicine. His research interests and accomplishments are focused in the areas of basic measurement research, descriptive studies of quality of life in chronic illness, psychosocial and behavioral health intervention, and the analysis and interpretation of patient-reported outcomes data in clinical trials. Prior to his work on PROMIS, Dr. Cella developed and validated a wide array of questionnaires, known collectively as the Functional Assessment of Chronic Illness Therapy Measurement System (FACIT), that are in wide use internationally.



Leah McClimans, PhD
University of South Carolina
Columbia, SC, United States

Leah McClimans is an associate professor in the philosophy department at the University of South Carolina. She is also currently a Marie Curie ASSITID Fellow at University College Cork's School of Nursing. Her research intersects philosophy of measurement with medical ethics. She has authored numerous articles on measurement in quality of life research, clinical ethics and the entanglement of ethics and evidence in medicine. Before coming to South Carolina, Leah was a post-doctoral fellow at the University of Toronto (2006-2007), and also held an Ethox Research Fellowship at the University of Warwick Medical School (2009-2010).



Laura Lee Johnson, PhD
U.S. Food and Drug Administration (FDA)
Silver Spring, MD, United States

Laura Lee Johnson, PhD is an acting division director and the Patient Focused Drug Development liaison for the Office of Biostatistics at the U.S. Food and Drug Administration (FDA) Center for Drug Evaluation and Research (CDER). She specializes in design, logistics, implementation, and analysis of research studies ranging from clinical outcome assessment (COA) qualification to trials of all sizes. She works across FDA on patient focused drug development initiatives. Prior to working at the FDA she spent over a decade at the U.S. National Institutes of Health working on and overseeing clinical research and research support programs.

Scientific Program — Wednesday, 24 October

Wednesday, 24 October

7:00 am – 7:00 pm Registration Desk Open Pre-function Area, Ground Floor

9:00 am – 4:00 pm IPRO Course (ticket required) Meeting Room 1, Second Floor

9:00 am – 4:00 pm IPCOR-Pharma Course (ticket required) Meeting Room 7, Second Floor

9:00 am – 12:00 pm Morning Workshops

WK01: Interpretation guidelines to define clinical relevance for Patient-Reported Outcome (PRO) measures Meeting Room 6, Second Floor

Sponsored By: Pfizer



Kim Cocks, PhD, Adelphi Values, UK, Cheshire, United Kingdom; **Kate Sully, PhD**, Adelphi Values, UK, Cheshire, United Kingdom; **Madeleine King, PhD**, University of Sydney, Sydney, Australia

WK02: Multilevel Data: A Look at Psychometric Analyses Meeting Room 9, Second Floor
Jan R. Boehnke, University of Dundee, Dundee, United Kingdom

WK03: What is Implementation Science and How Can It Help Us Integrate PROMs into Clinical Practice? Meeting Room 2, Second Floor

Angela Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; **Caroline Potter, DPhil**, University of Oxford, Oxford, United Kingdom; **Sara Ahmed, PT, PhD**, McGill University Health Center, Montreal, Quebec, Canada; **Amy Cizik, PhD, MPH**, University of Washington, Seattle, WA, United States; **Hedy van Oers, PhD candidate**, Academisch Medisch Centrum Universiteit van Amsterdam, Amsterdam, Netherlands; **Owis Eilayyan, PhD, PT Postdoctoral Fellow**, McGill University, Montreal, Quebec, Canada

WK04: Group Concept Mapping: Engaging Patients as Outcome Framework Co-Authors Meeting Room 5, Second Floor

Mary Kane, MSLIS, Concept Systems, Inc., Ithaca, NY, United States; **Emil Chiauzzi, PhD**, Patients Like Me, Cambridge, MA, United States

12:00 pm – 1:00 pm Lunch on your own

If you purchased boxed lunch via the registration form, please present your name badge to one of the hotel staff to pick up your Boxed Lunch in the reception area on the second floor.

Please note – Boxed lunches are **not available for purchase on-site.*

1:00 pm – 4:00 pm Afternoon Workshops

WK05: Clinical outcome assessment in a multi-cultural context: Measurement challenges and solutions Meeting Room 5, Second Floor

Sonya Eremenco, MA, Critical Path Institute, Tucson, AZ, United States; **Stacie Hudgens, MA (AbD)**, Clinical Outcomes Solutions, Tucson, AZ, United States; **Mona Martin, RN, MPA**, Health Research Associates, Inc., Mountlake Terrace, WA, United States; **Lori McLeod, PhD**, RTI Health Solutions, Research Triangle Park, NC, United States; **Antoine Regnault, PhD**, Modus Outcomes, Lyon, France

WK06: Clinical outcome assessments embedded in mobile and wearable information technologies Meeting Room 6, Second Floor

Katarzyna Wac, PhD, University of Geneva, Quality of Life Technologies Lab, Geneva, Switzerland; **Allan Berrocal, MS**, University of Geneva, Quality of Life Technologies Lab, Geneva, Switzerland

WK07: Back to the roots: the importance of applying theory to patient-reported outcomes measures (PROMs) validity testing Meeting Room 2, Second Floor

Melanie Hawkins, BA, BHSc, MPH, Deakin University, Melbourne, Australia; **Sandra Nolte, PhD**, Charité – Universitätsmedizin, Berlin, Germany; **Gerald Elsworth, BSc, PhD**, Deakin University, Melbourne, Australia; **Richard Osborne, BSc, PhD**, Deakin University, Melbourne, Australia

WK08: Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) – Qualitative Approaches for Data collection, Analyses and Reporting Meeting Room 9, Second Floor

Anne Skalicky, MPH, Evidera, Seattle, WA, United States; **Asha Hareendran, PhD**, Evidera, London, United Kingdom; **Susan Magasi, PhD**, University of Illinois at Chicago, Chicago, IL, United States

Scientific Program — Wednesday, 24 October

Wednesday, 24 October

4:30 pm - 6:00 pm

Industry Special Interest Group (I-SIG) Symposium

Pembroke & Herbert, Ground Floor

Meaning in movement: Defining valid endpoints using data collected with mobile technology tools

The age of mobile health monitoring tools is upon us. Pharmaceutical and biotechnology sponsors are developing, testing and implementing these innovative mobile technology tools, such as wearables, to capture continuous monitoring data in real time in clinical trials. Mobile technology tools may be used to collect activities or events (passive outcomes), as well as biomarker data (aka digital biomarker) or performance outcomes (i.e., PerFO). While the potential for mobile technology tools in terms of a real-world view of a patient's response to treatment, earlier decision making, and reduced costs because of fewer clinic visits is obvious, questions remain about the feasibility, variability, compliance, interpretability, and meaningfulness of the results. There is little available information on how patients view this data, its relevance to their lives and how changes in the kind of data collected by mobile technology tools (e.g., number of steps taken per day, number of hours slept, etc.) relate to changes in patients' perceptions of how they feel or function. The 2018 ISOQOL Annual Meeting Industry Special Interest Group (I-SIG) symposium will focus on how to define and construct meaningful clinical trial endpoints specific to activities and events (passive outcomes) using mobile technology tools, with examples presented. A panel discussion will highlight the key areas of concern when defining endpoints, and considerations for scoring, analysis, and reporting the evidentiary base for the interpretability of mobile technology results. A patient representative will participate in the panel to discuss their perspective on the uses and meaning of data collected with these technologies.

Moderator:

Linda Nelsen, GlaxoSmithKline, Collegeville, PA, United States

Speakers:

Anda Baharav, MD, SleepRate, Petah Tikva, Israel

Maggie Tabberer, MSc, GlaxoSmithKline, London, United Kingdom

Martin Daumer, PhD, SLCMSR e.V. – The Human Motion Institute, Munich, Germany

Panelists:

Wen-Hung Chen, PhD, U.S. Food and Drug Administration, Silver Spring, MD, United States

Sandra Zelinsky, Patient Scholar, University of Calgary, Calgary, Alberta, Canada

The I-SIG symposium is open to all annual conference participants. No ticket required.

6:00 pm - 7:30 pm

Welcome Reception & Celebration

Pre-function Area & Fitzwilliam Suites, Ground Floor

Join us as in celebration as ISOQOL commemorates the 25th Annual Conference. The welcome reception will include a ceremonial cake cutting, recognition of leaders, and a toast to the future (bring your gold ticket for a complimentary beverage). Begin your time at the conference by visiting with old friends and networking with new friends and colleagues. This is a celebration you won't want to miss!

The differences between success and failure often comes down to selecting and applying the right tools. For more than a decade, Vector Psychometric Group has helped clients leverage the power of advanced psychometric and statistical methods to achieve their goals. [Learn more at VPGCentral.com](http://VPGCentral.com)

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VECTOR
Psychometric Group

Scientific Program — Thursday, 25 October

7:00 am - 6:30 pm Registration Desk Open Pre-function Area, Ground Floor

7:30 am - 8:00 am First Time Attendee - Coffee with ISOQOL Board of Directors Meeting Room 1+2, Second Floor

First-time attendees to an ISOQOL annual conference are invited to meet the board of directors for an informal networking opportunity over coffee. This is also an opportunity to meet other first-time attendees.

8:15 am - 8:30 am Welcome and Opening Remarks Pembroke & Herbert, Ground Floor

Official welcome and opening remarks.

Joanne Greenhalgh, PhD and **Diana Rofail, PhD, CPsychol**, Scientific Program Co-Chairs

8:30 am - 10:00 am Plenary: Digital self-tracking to support patient self-management Pembroke & Herbert, Ground Floor

There is increasing interest in the digital collection and use of PRO data by patients to support self-management of long-term conditions. In this plenary, we will explore the opportunities and challenges of digital self-tracking from different perspectives.

Chair

Kevin Weinfurt, PhD, Duke University, Durham, NC, United States

Speakers

Elizabeth Murray, FRCGP, FRCP(Edin), PhD, University College London, London, United Kingdom

Bruce Hellman, MBA, uMotif, London, United Kingdom

Emma Rich, BSc, PhD, University of Bath, Bath, United Kingdom

10:00 am - 10:50 am Exhibits Open and Refreshment Break Fitzwilliam Suites, Ground Floor

10:10 am - 10:45 am Thursday Poster Session I Lansdowne Room, Ground Floor

(1003) The Patient-Reported Experience Measure for Improving qQuality of care in Mental health (PREMIUM) project in France: domain mapping process and item selection

Sara Fernandes, PhD student, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Guillaume Fond, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Xavier Zendjidjian, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Pierre-Michel Llorca, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Pierre Michel, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Pascal Auquier, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France; Laurent Boyer, Aix-Marseille Univ, School of medicine - La Timone Medical Campus, EA 3279: CEReSS - Health Service Research and Quality of Life Center, Marseille, France

OUTSTANDING POSTER AWARD FINALIST

(1005) Total hip arthroplasty: long-term health related quality of life outcomes

Amaia Bilbao, PhD, Research Unit, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain; Laura Ansola, MSc, Research Unit, Basurto University Hospital (Osakidetza), Bilbao, Spain; Juan Carlos Arenaza, MD, Traumatology and Orthopedic Surgery Service, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain; Jesus Azcarate, MD, Traumatology and Orthopedic Surgery Service, Mendaro Hospital (Osakidetza), Mendaro, Spain; Pedro Martin Esnaola, MD, Traumatology and Orthopedic Surgery Service, Donostia University Hospital (Osakidetza), Donostia, Spain; Ziortza Trancho, MSc, Research Unit, Basurto University Hospital (Osakidetza), Bilbao, Spain; Jose Maria Quintana, MD, PhD, Research Unit, Galdakao-Usansolo Hospital (Osakidetza) - REDISSEC, Galdakao, Spain; Antonio Escobar, MD, PhD, Research Unit, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain

OUTSTANDING POSTER AWARD FINALIST

(1007) Association between Neuro-QoL Scale Scores and Employment Status in MS PATHS (Multiple Sclerosis Partners Advancing Technology and Health Solutions) Patients.

Deborah Miller, PhD, LISW-S, Cleveland Clinic Mellen Center, Cleveland, OH, United States; Ellen Mowry, MD, MCR, Neurology and Epidemiology, Johns Hopkins Universtiy, Baltimore, MD, United States; Sarah Planchon, PhD, Mellen Center, Cleveland Clinic, Clevelaend, OH, United States; Carl de Moore, PhD, Value Based Medicine, Biogen, Cambridge, MA, United States; Robert Bermel, MD, Mellen Center, Cleveland Clinic, Cleveland, OH, United States

OUTSTANDING POSTER AWARD FINALIST

Cervical and Ovarian Cancer

(1009) Long term gynaecological cancer survivors in Côte d'Or: health-related quality of life, social and professional reinsertion

Ariane Mamguem Kamga, PhD Student, Epidemiology and Quality of Life Research Unit, Inserm U1231, Georges François Leclerc Centre, Dijon, France; Agnès Dumas, PhD, Centre for Research in Epidemiology and Population Health (CESP), INSERM U1018, University of Paris-Saclay, Gustave Roussy Institute, Villejuif, France; Florence Joly, MD, PhD, University Hospital Côte de Nacre, François Baclesse Comprehensive Cancer Centre, Medical Oncology Department, Inserm 1086, Caen, France; **Oumar Billa, MD, MSc, Epidemiology and Quality of Life Research Unit, Inserm U1231, Georges François Leclerc Centre, Dijon, France;** Julien Simon, PhD Student, Breast and Gynaecologic Cancer Registry of Côte d'Or, Georges François Leclerc Centre, Dijon, France; Marie-Laure Poillot, MSc, Epidemiology and Quality of Life Research Unit, Inserm U1231, Georges François Leclerc Centre, Dijon, France; Ariane Darut-Jouve, MD, Oncology Centre du parc, Dijon, France; Pierre Fumoleau, MD, PhD, Medical Oncology, Curie Institute, Paris, France; Charles Coutant, MD, PhD, Medical Oncology, Georges François Leclerc Centre, Dijon, France; Patrick Arveux, MD, PhD, HDR, Epidemiology and Quality of Life Research Unit, Inserm U1231, Georges François Leclerc Centre, Dijon, France; Tienhan Sandrine Dabakuyo-Yonli, PharmD, PhD, HDR, Epidemiology and Quality of Life Research Unit, Inserm U1231, Georges François Leclerc Centre, Dijon, France

(1011) The Influence of Survivor-specific Distress on Quality of Life among Long-term Ovarian Cancer Survivors

Lari Wenzel, University of California, Irvine, Irvine, CA, United States; Kathryn Osann, PhD, University of California Irvine, Irvine, CA, United States; Giulia Fulci, PhD, University of Alabama, Birmingham, AL, United States; Aditi Wahi, MPH, University of California Irvine, Irvine, CA, United States; Chelsea McKinney, PhD, University of California Irvine, Irvine, CA, United States; Michael Birrer, MD PhD, University of Alabama, Birmingham, AL, United States

Clinical Trials Methods

(1013) On the use of percent change outcomes in clinical trials

Carrie Houts, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States; James McGinley, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States; RJ Wirth, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

(1015) Development of a core outcome set capturing key concepts relevant to safe and efficient evaluation of innovative invasive procedures

Kerry Avery, BSc, PhD, University of Bristol, Bristol, United Kingdom; Shelley Potter, University of Bristol, Bristol, United Kingdom; Nicholas Wilson, University of Bristol, Bristol, United Kingdom; Rhiannon Macefield, University of Bristol, Bristol, United Kingdom; Rob Hinchliffe, University of Bristol, Bristol, United Kingdom; Sian Cousins, University of Bristol, Bristol, United Kingdom; Natalie Blencowe, University of Bristol, Bristol, United Kingdom; Daisy Elliott, University of Bristol, Bristol, United Kingdom; Barry Main, University of Bristol, Bristol, United Kingdom; Angus McNair, University of Bristol, Bristol, United Kingdom; Jane Blazeby, University of Bristol, Bristol, United Kingdom

(1017) Use of qualitative interviews in a developmental therapeutic clinical trial to guide refinement of content domain within an existing PRO instrument

Loretta A. Williams, PhD, APRN, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charlotte C. Sun, DrPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Shireen Haq, BS, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Katerina Savelieva, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, MD, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Robert L. Coleman, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Shannon Neville Westin, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Gordon B. Mills, MD, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Larissa Meyer, MD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

(1019) When PRO Science meets Regulatory Policies : Choosing Patient reported Outcome Tools for Industry Clinical Trials in Germany

Monika Bullinger, University Hospital Hamburg Eppendorf, Hamburg, Germany; Hidayet Metin, MBA, Janssen Cielag, Neuss, Germany; Susanne Huschens, Dr, Janssen Cielag, Neuss, Germany; Nicole Erdmann, Janssen Cielag, Neuss, Germany

(1021) Comparison of statistical methods for the analysis of patient-reported outcomes in RCTS

Stephen Walters, PhD, University of Sheffield, Sheffield, United Kingdom; Tracey Young, PhD, University of Sheffield, Sheffield, United Kingdom; Joseph Kwon, MSc, University of Sheffield, Sheffield, United Kingdom

(1023) Can parametric approaches be used to analyze Likert data from varying underlying distributions including those with unimodal or bimodal shape or extreme floor/ceiling effects? A simulation study.

Todd DeWees, PhD, Mayo Clinic, Scottsdale, AZ, United States; Gina L Mazza, PhD, Mayo Clinic, Scottsdale, AZ, United States; Amylou C Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States

EQ-5D

(1025) Exploring the importance of time during the Feedback Module in the EQ-5D-5L valuations: results from Ireland.

Anna Hobbins, B.Comm., MSc, Queen's University, Belfast, United Kingdom; Luke Barry, National University of Ireland, Galway, Ireland; Daniel Kelleher, National University of Ireland, Galway, Ireland; Ciaran O'Neill, Queen's University, Belfast, United Kingdom

(1027) EQ-5D-3L vs. EQ-5D-5L: A cross-sectional comparison of measurement properties among total hip and knee replacement patients

Xuejing Jin, School of Public Health, University of Alberta, Edmonton, Alberta, Canada; Fatima Al Sayah, PhD., School of Public Health, University of Alberta, Edmonton, Alberta, Canada; **Arto Ohinmaa, PhD., School of Public Health, University of Alberta, Edmonton, Alberta, Canada**; Deborah Marshall, PhD., Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Jeffery Johnson, PhD., School of Public Health, University of Alberta, Edmonton, Alberta, Canada

(1029) Predictors of self-reported health-related quality of life according to the EQ-5D-Y in chronically ill children and adolescents with asthma, diabetes, and juvenile arthritis: longitudinal results

Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Dana Barthel, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klasen, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Matthias Rose, Prof. PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Ann-Katrin Meyrose, M.Sc., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Marcus Klein, Dr. med., University Medical Center, Kiel, Germany; Ute Thyen, Prof. Dr.med., University of Lübeck, Lübeck, Germany; Ulrike Ravens-Sieberer, Prof. PhD, MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1031) Comparing self-reported Health-Related Quality of Life of Polish migrants living in Ireland with the native population using the EQ-5D-5L.

Dan Kelleher, B.Comm, MSc., NUI Galway, Galway, Ireland; Luke Barry, B.Comm, MSc., NUI Galway, Galway, Ireland; Anna Hobbins, B.Comm, MSc., Queen's University Belfast, Belfast, United Kingdom; Ciaran O'Neill, BSc, Ph.D., Queen's University Belfast, Belfast, United Kingdom

(1033) An investigation into the validity of the EQ-5D-5L, SF-12, ASCOT and WEMWBS in older people using item response theory and differential item functioning

Hannah Penton, University of Sheffield, Sheffield, United Kingdom; Tracey Young, BSc MSc PhD, University of Sheffield, Sheffield, United Kingdom; Christopher Dayson, BA MA, Sheffield Hallam University, Sheffield, United Kingdom; Claire Hulme, BSc MA PhD, University of Leeds, Leeds, United Kingdom

(1035) EQ-5D-5L utility values for patients who underwent a programmed surgical procedure with institutionalization in the last year according to their smoking status in Spain

Javier Rejas, MD, Universidad Carlos III, Madrid, Spain; Miguel Ruiz, PhD, Universidad Autónoma de Madrid, Madrid, Spain

(1037) Withdrawn

(1039) Quality control of the data on the Portuguese study for the valuation of the EQ-5D-5L

Patricia Antunes, CEISUC, Coimbra, Portugal; Pedro Lopes Ferreira, CEISUC, Coimbra, Portugal; Lara Noronha Ferreira, CEISUC, Coimbra, Portugal; Luís Pereira, CEISUC, Coimbra, Portugal

(1041) Withdrawn

Head and Neck Cancer

(1043) Latent class analysis of fatigue in patients with head and neck cancer

Canhua Xiao, Emory University, Atlanta, GA, United States; Ronald Eldridge, Emory University, Atlanta, GA, United States; Kristin Higgins, Emory University, Atlanta, GA, United States; Nabil Saba, Emory University, Atlanta, GA, United States; Dong Shin, Emory University, Atlanta, GA, United States; Andrew Miller, Emory University, Atlanta, GA, United States; Deborah Bruner, Emory University, Atlanta, GA, United States; Jonathan Beitler, Emory University, Atlanta, GA, United States

(1045) A structured review of body image measures for head and neck cancer (HNC) and content mapping against existing frameworks

Chindhu Shunmugasundaram, M.Sc., M.Phil, University of Sydney, Sydney, Australia; Haryana Dhillon, PhD, University of Sydney, Sydney, Australia; Phyllis Butow, PhD, University of Sydney, Sydney, Australia; **Claudia Rutherford, PhD, University of Sydney, Sydney, Australia**; Puma Sundaresan, PhD, University of Sydney, Sydney, Australia

(1047) Head and Neck cancer: Quality of Life Assessment using Item Response Theory

Pedro Lopes Ferreira, CEISUC/FEUC, Coimbra, Portugal; Ana Rosa Castro, PhD, UFP, Porto, Portugal; Teresa Sequeira, PhD, CEISUC/UFP, Porto, Portugal; Feliz Gouveia, PhD, UFP, Porto, Portugal; Eurico Monteiro, PhD, IPOFG-Porto, Porto, Portugal; Lurdes Carvalho, RN, IPOFG-Porto, Porto, Portugal; Augusta Silveira, PhD, CEISUC/UFP, Porto, Portugal

(1049) An canonical correlation analysis on influence factors of quality of life in patients with head and neck cancer based on QLICP-HN questionnaire

Zheng Yang, Guangdong Medical University, Dongguan, China; Chonghua Wan, Guangdong Medical University, Dongguan, China; Qiong Meng, Kunming Medical University, Kunming, China; Jiahong Luo, Kunming Medical University, Kunming, China; Gaofeng Li, Kunming Medical University, Kunming, China; Yingli Cun, Kunming Medical University, Kunming, China

Linguistic and Cross-Cultural Validation

(1051) *Withdrawn*

(1053) Translation and Linguistic Validation of PROMIS® Itch Short Forms for Use with Patients Worldwide

Benjamin Arnold, MA, FACITtrans, Elmhurst, IL, United States; Miriam Kimel, PhD, Evidera, Bethesda, MD, United States; Helena Correia, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Lillian Savic, FACITtrans, Elmhurst, IL, United States; Emily Parks-Vernizzi, FACITtrans, Elmhurst, IL, United States; Barbara Perez, FACITtrans, Elmhurst, IL, United States; David Cella, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Jonathan Silverberg, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Robin Blumenthal, PhD, Menlo Therapeutics Inc., Redwood City, CA, United States

(1055) Are you able to cut your meat? – Exploring the challenges during the cultural adaptation of the Health Assessment Questionnaire Disability Index (HAQ-DI) into 130 languages

Catherine Acquadro, Mapi, an ICON plc Company, Lyon, France; **Caroline Anfray, Mapi Research Trust, Lyon, France;** Piero Bindi, Mapi Research Trust, Lyon, France; Virginia Uzun, Mapi, an ICON plc Company, Lyon, France

(1057) Cross-cultural adaptation of the Impact on Participation and Autonomy Questionnaire (IPA), English version, to Brazilian spinal cord injury patients.

Valeria Andrade, Federal University of Triângulo Mineiro, Uberaba, Brazil; Fabiana Faleiros Faleiros, DHSc, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Fernanda Karla Nascimento, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; **Beatriz Conacci, RN, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil;** Viviane Romeiro, BS, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Monica Mombelli, MSc, Dinâmica das Cataratas University Center, Foz do Iguaçu, Brazil; Monika Bullinger, PhD, University of Hamburg, Hamburg, Germany; Claudia Benedita Santos, PhD, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil

(1059) Measuring patients' Orofacial Appearance: validity and reliability of the English-language Orofacial Esthetic Scale

Daniel Reißmann, DDS, Dr Med Dent, MSc, PhD, Department of Prosthetic Dentistry, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Mike T. John, Department of Diagnostic and Biological Sciences, University of Minnesota, Minneapolis, MN, United States; William A. Rush, HealthPartners Institute for Education and Research, Minneapolis, MN, United States; Christopher J. Enstad, HealthPartners Institute for Education and Research, Minneapolis, MN, United States; Patricia Lenton, Oral Health Clinical Research Clinic, University of Minnesota, Minneapolis, MN, United States; Ira Sierwald, Department of Orthodontics, Dentofacial Orthopedics and Pedodontics, Charité – Universitätsmedizin Berlin, Berlin, Germany

(1061) Challenges in the cross-cultural validation of the Functional Vision Questionnaire for Children and Young People (FVQ_CYP) with visual impairment

Ellen Elsman, PhD Student, Amsterdam University Medical Centers, location VUmc, dept. of Ophthalmology, Amsterdam, Netherlands; Val Tadic, University College London, Institute of Child Health, London, United Kingdom; Carel Peeters, VU University Medical Centre, dept. of Epidemiology and Biostatistics, Amsterdam, Netherlands; Ger van Rens, VU University Medical Centre, dept. of Ophthalmology, Amsterdam, Netherlands; Jugnoo Rahi, University College London, Institute of Child Health, London, United Kingdom; Ruth van Nispen, VU University Medical Centre, dept. of Ophthalmology, Amsterdam, Netherlands

(1063) Intercultural validation of the YHC-SUN short-form assessing health care satisfaction in adolescents with a chronic condition

Holger Muehlan, University of Greifswald, Department Health & Prevention, Greifswald, Germany; Silke Schmidt, Professor, University of Greifswald, Department Health & Prevention, Greifswald, Germany; Kristina Stumpf, Dipl.-Psych., University of Greifswald, Department Health & Prevention, Greifswald, Germany; Birgit Koehlerb, MD, Charity - University Medicine of Berlin, Institute for Experimental Paediatric Endocrinology, Berlin, Germany; Marion Rapp, PhD, University of Luebeck, Department of Paediatrics & Adolescent Medicine, Luebeck, Germany; Ute Thyen, Professor, University of Luebeck, Department of Paediatrics & Adolescent Medicine, Luebeck, Germany

(1065) Differential Item Functioning by Language for PROMIS Physical Function Items: Application of a Confirmatory Factor Approach for Ordered Categorical Responses

John Peipert, PhD, Northwestern University, Chicago, IL, United States; Aaron Kaat, PhD, Northwestern University, Chicago, IL, United States; Benjamin Schalet, PhD, Northwestern University, Chicago, IL, United States; Felix Fischer, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Caroline Terwee, PhD, VU University Medical Center, Amsterdam, Netherlands; David Cella, PhD, Northwestern University, Chicago, IL, United States

(1067) Life-Space Assessment scale to assess Portuguese older adults mobility: Cross-cultural adaptation and validation

Liliana Santos Ferreira, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; **Luís Cavalheiro, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal;** Francisca Fernandes, PT, MSc, College of Health Alcoitão, Portugal, Estoril, Portugal; Rui Soles Gonçalves, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Pedro Lopes Ferreira, PhD, University of Coimbra, Centre for Health Studies and Research, Coimbra, Portugal

(1069) Spanish patient reported outcomes in the 2005-2014 decade: the Bibliopro periodic systematic review

Yolanda Pardo, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Cristina Oriol, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Olatz Garin, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Gemma Vilagut, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Carlos García-Forero, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Marc Martí, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Itxaso Alayo, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Víctor Zamora-Ruiz, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; **Montserrat Ferrer, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain;** Jordi Alonso, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Scientific Committee Bibliopro, Committee, Barcelona, Spain

(1071) Dutch Translation and Linguistic Validation of the U.S. National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE)

Aaltje E. Veldhuijzen, The Netherlands Cancer Institute, Amsterdam, Netherlands; Jose S.A. Belderbos, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; Sandra A. Mitchell, PhD, Outcomes Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, United States; Shawn M. McKown, MA, RWS, East Hartford, CT, United States; Matthew Lauritzen, BA, RWS, East Hartford, CT, United States; Elizabeth Yohe Moore, MPH, RWS, East Hartford, CT, United States; Katherine J. Kim, MPH, Genentech, Inc., South San Francisco, CA, United States; Iris Walraven, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands; **Neil K Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, Netherlands**

(1073) Same language, different culture: Differential item functioning and factor structure of the DISABKIDS-37 questionnaire in Portuguese and Brazilian children/adolescents with asthma and diabetes

Neuza Silva, PhD, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Claudia dos Santos, Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto, Ribeirão Preto, São Paulo, Brazil; Carlos Carona, Cerebral Palsy Association of Coimbra, Coimbra, Portugal; Serlyjane Nunes, Universidade Federal do Maranhão, Departamento de Ciências Fisiológicas, Centro de Ciências Biológicas e da Saúde, São Luís, Maranhão, Brazil; Helena Moreira, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Claudia Fegadolli, Universidade Federal de São Paulo, Instituto de Ciências Ambientais, Químicas e Farmacêuticas, Departamento de Ciências Farmacêuticas, São Paulo, São Paulo, Brazil; Maria Cristina Canavaro, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Monika Bullinger, Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1075) Knee Outcome Survey - Sports Activity Scale questionnaire in Portuguese athletes with anterior cruciate ligament injury or reconstruction: cross-cultural adaptation and validation

Rui Soles Gonçalves, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Joana Oliveira Rosado, PT, MSc, Rainha Santa Isabel Center, Diocesan Caritas of Coimbra, Coimbra, Portugal; Luís Manuel Cavalheiro, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Pedro Lopes Ferreira, PhD, University of Coimbra, Centre for Health Studies and Research, Coimbra, Portugal; João Páscoa Pinheiro, MD, PhD, University of Coimbra, Faculty of Medicine, Coimbra, Portugal; Jan Cabri, PT, PhD, Norwegian School of Sport Sciences, Department of Physical Performance, Oslo, Norway

(1077) The importance of concept elaboration guides in linguistic validation and recommendations for development

Shawn McKown, RWS Life Sciences, East Hartford, CT, United States; Barbara Brandt, RWS Life Sciences, East Hartford, CT, United States; Tim Poepsel, RWS Life Sciences, Chicago, IL, United States; Elizabeth Yohe Moore, RWS Life Sciences, Chicago, IL, United States; Elizabeth McCullough, RWS Life Sciences, East Hartford, CT, United States

(1079) Dutch and Danish translation and cultural adaption of the WOUND-Q.

Tert van Alphen, MD MBA, Brigham and Women's Hospital. Harvard Medical School., Boston, MA, United States; Emiel van Haren, MD, Catharina Hospital, Eindhoven, Netherlands; Lotte Poulsen, MD, Odense University Hospital, Odense, Denmark; Jens Ahm Sørensen, MD PhD, Odense University Hospital, Odense, Denmark; Anne Klassen, DPhil, Mc Master University Hamilton, Hamilton, Ontario, Canada; Maarten Hoogbergen, MD PhD, Catharina Hospital, Eindhoven, Netherlands; Andrea Pusic, MD PhD, Brigham and Women's Hospital. Harvard Medical School. Jens Ahm Sorensen, Boston, MA, United States

Neurological Conditions

(1081) Implementation of the PREM 'This is how I feel about it!' in a long-term care facility for people with acquired brain injuries. An embedded case study

Marjolein van Rooijen, Maastricht University, Maastricht, Netherlands; Albine Moser, PhD, Zuyd University of applied sciences, Heerlen, Netherlands; Stephanie Lenzen, MSc, Zuyd University of applied sciences, Heerlen, Netherlands; **Anna Beurskens, PhD, Prof, Zuyd University of applied sciences, Heerlen, Netherlands**

(1083) Do generic preference-based measures capture what is important to the quality of life of people with Parkinson's Disease?

Ayşe Kuspinar, BSc(PT), MSc, PhD, McMaster University, Hamilton, Ontario, Canada; Kedar Mate, MSc, PhD(c), McGill University, Montreal, Quebec, Canada; Nancy Mayo, BSc(PT), MSc, PhD, McGill University, Montreal, Quebec, Canada

(1085) International validation of the Spanish version of the Parkinson's Disease Sleep Scale 2 (PDSS-2)

Carmen Rodríguez-Blázquez, Instituto de Salud Carlos III, Madrid, Spain; John Wetmore, Instituto de Salud Carlos III, Madrid, Spain; Marcos Serrano-Dueñas, Medicine Faculty, Pontifical Catholic University of Ecuador, Neurological Service, Carlos Andrade Marin Hospital., Quito, Ecuador; Ivon Pedroso, International Neurological Restoration Center (CIREN), Havana, Cuba; Juan Carlos Martínez-Castrillo, Neurology Department, IRYCIS, Ramón y Cajal Hospital, Madrid, Spain; Oscar Bernal, Military Hospital, Santa Fe de Bogotá Foundation, Bogotá, Colombia; Tomoko Arakaki, Movement Disorders Section, Department of Neurology, Ramos Mejía Hospital, Buenos Aires, Argentina; Nélica Garretto, Movement Disorders Section, Department of Neurology, Ramos Mejía Hospital, Buenos Aires, Argentina; Mayela Rodríguez-Violante, Movement Disorders Unit, National Institute of Neurology and Neurosurgery, México City, Mexico; Víctor Campos, Neurology Department, Vithas-Málaga Hospitals, Málaga, Spain; Ingrid Estrada-Bellmann, University Hospital, Monterrey, Mexico; Christopher Cerda, University Hospital, Monterrey, Mexico; Francisco Vivancos-Matellano, University Hospital La Paz, Madrid, Spain; Jorge Uriel Mániz-Miró, University Hospital La Paz, Madrid, Spain; Pablo Martínez-Martín, Instituto de Salud Carlos III, Madrid, Spain

(1087) Measurement of treatment goals, treatment benefit, and disease burden in multiple sclerosis: validation of a new tool set

Helen Beckmann, University Medical Center Hamburg, Hamburg, Germany; Matthias Augustin, Prof. MD, University Medical Center Hamburg, Hamburg, Germany; Jana Poettgen, Ph.D., University Medical Center Hamburg, Hamburg, Germany; Christoph Heesen, Prof. Dr., University Medical Center Hamburg, Hamburg, Germany; **Christine Blome, Ph.D., University Medical Center Hamburg, Hamburg, Germany**

(1089) Broadening the evaluative scope of economic evaluations: investigating the construct validity and responsiveness of the ICECAP-O instrument in Parkinson's disease

Yiqiao Xin, Health Economics and Health Technology Assessment (HEHTA), Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom; Jim Lewsey, Health Economics and Health Technology Assessment (HEHTA), Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom; Richard Gray, Clinical Trial Service Unit and Epidemiological Studies Unit, University of Oxford, Oxford, United Kingdom; Carl Clarke, Institute of Applied Health Research, University of Birmingham, Sandwell and West Birmingham Hospitals NHS Trust, Birmingham, United Kingdom; Joanna Coast, School of Social and Community Medicine, University of Bristol, Bristol, United Kingdom; Caroline Rick, Birmingham Clinical Trials Unit (BCTU), Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; **Emma McIntosh, Health Economics and Health Technology Assessment (HEHTA), Institute of Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom**

(1091) The experience of physical activity for children with epilepsy from the child's and parent's perspective using the International Classification of Functioning, Disability, and Health

Jessica Willis, School of Medicine, National University of Ireland, Galway, Galway, Ireland; Lauren Hopping, Michael G. Degroote School of Medicine, McMaster University, Hamilton, Ontario, Canada; Gabriel M Ronen, Department of Pediatrics, McMaster University, Hamilton, Ontario, Canada

(1093) Rasch analysis of the Oswestry disability index in patients with pain caused by thoracolumbar degenerative spinal disease

Jussi Repo, Department of Surgery, Central Finland Central Hospital, Jyväskylä, Finland; Kati Kyrölä, MD, PhD, Department of Surgery, Central Finland Central Hospital, Jyväskylä, Finland; Jari Ylinen, MD, PhD, Department of Physical Medicine and Rehabilitation, Central Hospital of Central Finland, Jyväskylä, Finland; Liisa Pekkanen, MD, PhD, Department of Surgery, Central Finland Central Hospital, Jyväskylä, Finland; Mike Horton, PhD, Psychometric Laboratory for Health Sciences, University of Leeds, Leeds, United Kingdom; Arja Häkkinen, PhD, Department of Health Sciences, University of Jyväskylä, Jyväskylä, Finland

(1095) Withdrawn

(1097) Blog reviews as a supplemental method to identify symptoms and impacts of systemic amyloidosis

Josephine Park, MPH, MBA, GlaxoSmithKline, Collegeville, PA, United States; Katy Benjamin, PhD, ICON, Gaithersburg, MD, United States; Jennifer Devlen, PhD, ICON, Gaithersburg, MD, United States; Ryan Murphy, PhD, ICON, Gaithersburg, MD, United States; Christina O'Donnell, PhD, ICON, Gaithersburg, MD, United States; Robyn von Maltzahn, GlaxoSmithKline, London, United Kingdom; **Kelly Lipman, MPH, ICON, Gaithersburg, MD, United States**

(1099) Patient-reported outcome (PRO) measure-based algorithm for clinical decision support in epilepsy outpatient follow-up: a test-retest reliability study

Liv Marit Valen Schougaard, AmbuFlex, Regional Hospital West Jutland, Herning, Denmark; Annette de Thurah, Department of Rheumatology, Aarhus University Hospital, Aarhus, Denmark; David Høyrup Christiansen, Department of Occupational Medicine, Regional Hospital West Jutland, Herning, Denmark; Niels Henrik Hjøllund, WestChronic, Occupational Medicine, Regional Hospital West Jutland, Herning, Denmark

(1101) Patients' information needs in multiple sclerosis and their relation with patient profiles

Miguel A. Ruiz, Universidad Autónoma de Madrid, Madrid, Spain; Virginia Meca-Lallana, MD, Hospital Universitario de La Princesa, Madrid, Spain; María Brañas, Phar, Roche Pharma, Madrid, Spain; Yolanda Higuera, NeuPsi, Instituto de investigación sanitario Gregorio Maraón, Madrid, Spain; Jorge Mauriño, MD, Roche Pharma, Madrid, Spain

(1103) A new PROMIS physical function short form for use in relapse and progressive multiple sclerosis types

Paul Kamudoni, Global Evidence & Value Development, Merck KgaA, Darmstadt, Germany; Christian Henke, PhD, Global Evidence & Value Development, Merck KgaA, Darmstadt, Germany; Amy Barrett, MSPH, MA, RTI Health Solutions, Durham, NC, United States; Ari Gnanasakthy, MBA, MSc, RTI Health Solutions, Durham, NC, United States; Amtmann Dagmar, PhD, University of Washington, Seattle, WA, United States; Karon Cook, PhD, Feinberg School of Medicine, Northwestern University, Chicago, IL, United States; Jana Raab, MSc, Global Evidence and Value Development, Merck KgaA, Darmstadt, Germany; Oliver Guenther, PhD, Global Evidence & Value Development, Merck KgaA, Darmstadt, Germany

(1105) Mobility Measures among Individuals with Acquired Brain Injury (ABI): An Umbrella Review

Rehab Alhasani, McGill University, Montreal, Quebec, Canada; Claudine Auger, OT, PhD, Université de Montréal, Montreal, Quebec, Canada; Matheus de Paiva Azevedo, PT BSc., Federal University of Rio Grande do Norte, Camara, Brazil; Sara Ahmed, PT, PhD, McGill University, Montreal, Quebec, Canada

(1107) Assessing response shift in health related quality of life measures when formative indicators are employed

Rosalba Rosato, Università di Torino, Torino, Italy; **Silvia Testa, Department of Psychology University of Turin, Turin, Italy;** Daniela Di Cuonzo, Department of Psychology University of Turin, Turin, Italy; Eva Pagano, Unit of Clinical Epidemiology, "Città della Salute e della Scienza" Hospital, Turin, Italy; Giuliana Ritorto, SSCVD ColoRectal Cancer Unit-Oncologia 1-Department of Oncology "Città della Salute e della Scienza" Hospital, Turin, Italy; Marcello Zanini, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology "Città della Salute e della Scienza" Hospital, Turin, Italy; Patrizia Racca, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology "Città della Salute e della Scienza" Hospital, Turin, Italy

Oesophageal Cancer

(1109) Education level and health-related quality of life after oesophageal cancer surgery

Anna Schandl, Karolinska Institutet, Stockholm, Sweden; Asif Johar, Karolinska Institutet, Stockholm, Sweden; Kalle Mälberg, Karolinska Institutet, Stockholm, Sweden; Pernilla Lagergren, Karolinska Institutet, Stockholm, Sweden

(1111) Self-assessed health related quality of life among 10-year survivors after oesophageal cancer surgery

Cecilia Haddad Ringborg, PhD Student, Karolinska Institute, Department of Molecular Medicine and Surgery, Surgical Care Science, Stockholm, Sweden; Asif Johar, Statistician, Karolinska Institute, Department of Molecular Medicine and Surgery, Surgical Care Science, Stockholm, Sweden; Pernilla Lagergren, Professor, Karolinska Institute, Department of Molecular Medicine and Surgery, Surgical Care Science, Stockholm, Sweden

(1113) Health-related quality of life during palliative systemic therapy for oesophagogastric cancer: a systematic review

Jessy Joy van Kleef, MSc, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Emil ter Veer, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Héctor van den Boorn, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Mariska Prins, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Lok Lam Ngai, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Nadia Haj Mohammad, Department of Medical Oncology, University Medical Center Utrecht, Utrecht, Netherlands; Lonneke van de Poll-Franse, Department of Research, Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, Netherlands; Aeilko Zwinderman, Department of Clinical Epidemiology, Biostatistics and Bioinformatics, Academic Medical Center, Amsterdam, Netherlands; Martijn van Oijen, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Hanneke van Laarhoven, Cancer Center Amsterdam, Academic Medical Center, University of Amsterdam, Department of Medical Oncology, Amsterdam, Netherlands; Mirjam Sprangers, Amsterdam Public Health, Academic Medical Center, University of Amsterdam, Department of Medical Psychology, Amsterdam, Netherlands

(1115) Extent of dumping symptoms and its association with malnutrition following surgery for oesophageal cancer

Poorna Anandavadivelan, Karolinska Institutet, Stockholm, Sweden; Anna Wikman, Reproductive Health, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden; Lena Martin, Department of Biosciences and nutrition, Stockholm, Sweden; Claudia Rueb, St Mary's Hospital, Imperial College Healthcare NHS Trust, London, United Kingdom; Asif Johar, Surgical Care Sciences, Department of Molecular medicine and Surgery, Karolinska Institutet, Stockholm, Sweden; Kalle Malberg, Surgical Care Sciences, Department of Molecular medicine and Surgery, Karolinska Institutet, Stockholm, Sweden; Pernilla Lagergren, Surgical Care Sciences, Department of Molecular medicine and Surgery, Karolinska Institutet, Stockholm, Sweden

(1117) The influence of psychological distress on the recovery of health-related quality of life in post-operative oesophageal cancer patients

Yangjun Liu, Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institute, Karolinska University Hospital, Stockholm, Sweden; Anna Schandl, Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institute, Karolinska University Hospital, Stockholm, Sweden; Sheraz Markar, Department of Surgery and Cancer, Imperial College London, London, United Kingdom; Asif Johar, Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institute, Karolinska University Hospital, Stockholm, Sweden; Pernilla Lagergren, Surgical Care Science, Department of Molecular Medicine and Surgery, Karolinska Institute, Karolinska University Hospital, Stockholm, Sweden

Tolerability

(1119) PRO-CTCAE in the management of adverse effects in patients receiving immunotherapy for metastatic melanoma – an ongoing randomized clinical trial

Lærke K. Tolstrup, Odense University Hospital, Odense, Denmark; Helle Pappot, MD, PhD, Copenhagen University Hospital, Rigshospitalet, Copenhagen, Denmark; Karin B. Dieperink, RN, PhD, Post-doc, Department of Oncology, Odense University Hospital, Odense, Denmark; Ann-Dorthe O. Zwisler, MD, PhD, Professor, REHPA – Danish Knowledge Centre for Rehabilitation and Palliative Care, Nyborg, Denmark; Lars Bastholt, MD, Department of Oncology, Odense University Hospital, Odense, Denmark

(1121) Longitudinal patient-reported outcomes (PROs) and qualitative assessment of symptom burden within a phase 1b trial of a PARP inhibitor olaparib combined with an oral mTORC1/2 inhibitor (AZD2014) or an AKT inhibitor (AZD5363)

Larissa A Meyer, MD MPH, The University of Texas MD Anderson Cancer Center, Department of Gynecologic Oncology and Reproductive Medicine, Houston, TX, United States; Charlotte Sun, DrPH, The University of Texas MD Anderson Cancer Center, Department of Gynecologic Oncology and Reproductive Medicine, Houston, TX, United States; Qiuling Shi, PhD, The University of Texas MD Anderson Cancer Center, Department of Symptoms Research, Houston, TX, United States; Shannon Westin, MD, The University of Texas MD Anderson Cancer Center, Department of Gynecologic Oncology and Reproductive Medicine, Houston, TX, United States; Shireen Haq, BS, The University of Texas MD Anderson Cancer Center, Department of Symptoms Research, Houston, TX, United States; Katerina Savelieva, PhD, The University of Texas MD Anderson Cancer Center, Department of Systems Biology, Houston, TX, United States; Robert Coleman, MD, The University of Texas MD Anderson Cancer Center, Department of Gynecologic Oncology and Reproductive Medicine, Houston, TX, United States; Gordon Mills, MD PhD, The University of Texas MD Anderson Cancer Center, Department of Systems Biology, Houston, TX, United States; Loretta Williams, PhD RN, The University of Texas MD Anderson Cancer Center, Department of Symptoms Research, Houston, TX, United States

(1123) Patients' preference of cancer symptom patient reported outcomes measures.

Meagan Whisenant, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Oluwatosin Bamidele, MBBS, MPH, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles Cleeland, PhD, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Loretta A. Williams, PhD, ARPN, The University of Texas MD Anderson Cancer Center, Houston, TX, United States

(1125) Mapping Child and Adolescent Self-Reported Symptom Data to Clinician-Reported Adverse Event Grading to Improve Pediatric Oncology Care and Research

Molly McFatrach, MPH, Duke University, Durham, NC, United States; Jennifer Brondon, MD, MS, Duke University, Durham, NC, United States; Nicole Lucas, BS, Duke University, Durham, NC, United States; Justin N. Baker, MD, FAAP, FAAHPM, St. Jude Children's Research Hospital, Memphis, TN, United States; Sharon Castellino, MD, MSc, Emory University, Atlanta, GA, United States; Pamela S. Hinds, PhD, RN, FAAN, Children's National Health System, Washington, DC, United States; Shana Jacobs, MD, Children's National Health System, Washington, DC, United States; Catriona Mowbray, PhD, BSN, RN, CPN, Children's National Health System, Washington, DC, United States; Bryce B. Reeve, PhD, Duke University, Durham, DC, United States

(1127) Patient-reported Symptom Interference as a Potential Measure for Tolerability of Cancer Treatment: evidence from ECOG-ACRIN SOAPP

Qiuling Shi, PhD, University of Texas MD Anderson Cancer Center, Houston, TX, United States; Ju-Whei Lee, PhD, Dana-Farber Cancer Institute, Boston, MA, United States; Xin Wang, MD, University of Texas MD Anderson Cancer Center, Houston, TX, United States; Michael J. Fisch, MD, MPH, AIM Specialty Health, Chicago, IL, United States; Judith Manola, MS, Dana-Farber Cancer Institute, Boston, MA, United States; Lynne Wagner, PhD, Wake Forest University Health Services, Winston-Salem, NC, United States; Victor T. Chang, MD, VA New Jersey Health Care System, East Orange, NJ/UMDNJ, Newark, NJ, United States; Charles S. Cleeland, PhD, University of Texas MD Anderson Cancer Center, Houston, TX, United States

(1129) The healthcare employees' burnout in urban community health centers under coverage of Universities of Medical Sciences in Tehran

Farahnaz Khajehnasiri, PhD, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Shahla Khosravi, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Soheila Dabiran, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Azita Khiltash, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran

(1131) Late-Career Unemployment has Mixed Effects in Retirement

Maren Voss, ScD, University of Utah, Salt Lake City, UT, United States; Lori Wadsworth, PhD, Brigham Young University, Provo, UT, United States; Wendy Birmingham, PhD, Brigham Young University, Provo, UT, United States; Beth Merryman, PhD, Towson University, Towson, MD, United States; Lisa Crabtree, PhD, Towson University, Towson, MD, United States; Man Hung, PhD, University of Utah, Salt Lake City, UT, United States

Scientific Program — Thursday, 25 October

Thursday, 25 October

10:50 am - 12:00 pm Plenary: Cutting Edge Research Pembroke & Herbert, Ground Floor

Sponsored by: Vector Psychometric Group



This plenary session features some of the highest-ranked, most innovative research from ISOQOL abstract submissions. In particular, these abstracts span the research continuum and reflect research that truly “pushes the ISOQOL envelope” in providing new and different ways to look at quality of life.

Chair

Tom Willgoss, PhD, Roche Products Ltd., Welwyn Garden City, United Kingdom

Speakers

Leveraging Big Data analytics in processing free-text entries of personal goals among patients undergoing bladder cancer surgery

Yuelin Li, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States

Visualization of Patient-Reported Experience Measures: Opportunities for Quality and Health System Improvements

Kyle Kemp, MSc, PhD Candidate, University of Calgary, Calgary, Alberta, Canada

Longitudinal patient-reported cumulative symptom burden as an indicator of chronic health conditions in adult survivors of childhood cancer: a follow-up study of 25 years

I-Chan Huang, PhD, St. Jude Children’s Research Hospital, Memphis, TN, United States

Analysis of early predictive lung cancer symptoms and sensations by orthogonal projections to latent structures (OPLS)

Adrian Levitsky, PhD, Division of Innovative Care Research, Department of Learning, Informatics, Management, and Ethics (LIME); Department of Oncology-Pathology, Science for Life Laboratory, Karolinska Institutet, Stockholm, Sweden

12:00 pm - 1:45 pm Buffet Lunch Break Sussex Restaurant, Ground Floor

12:05 pm – 12:50 pm

First Lunch Shift

1:00 pm – 1:45 pm

Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Sussex Restaurant on the Ground Floor. Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. Entry into the restaurant is by name badge.

12:10 pm - 1:05 pm Special Interest Group (SIG) Meetings

Child Health SIG Meeting	Meeting Room 1+2
Health Preference Research SIG Meeting	Meeting Room 9
Industry SIG Meeting	Meeting Room 5
Mixed Methods SIG Meeting	Meeting Room 6
Patient Engagement SIG Meeting	Pembroke & Herbert
QLR Editorial Board Meeting (closed event)	Meeting Room 7

1:45 pm - 3:15 pm Concurrent Oral Sessions

Oral Session 101: Interpreting Meaningful Change Meeting Room 1+2

Session Chair: Hannah Staunton, MSc, United Kingdom

1:50 pm – 2:07 pm (101.1) Triangulating estimates of meaningful change or difference in patient-reported outcomes: application of a correlation-based weighting procedure

Amelia Harper, Adelphi Values, Manchester, United Kingdom; Claire Trennery, MSc, Adelphi Values, Manchester, United Kingdom; Kate Sully, PhD, Adelphi Values, Manchester, United Kingdom; **Andrew Trigg, MSc, Adelphi Values, Manchester, United Kingdom**

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

Scientific Program — Thursday, 25 October

2:08 pm – 2:25 pm (101.2) How to simulate responses to items and to an anchor question with a known Minimal Clinically Important Difference value? The proposal of a simulation model.

Antoine Vanier, Inserm U1246 SPHERE - University of Nantes, Nantes, France; Myriam Blanchin, PhD, Inserm U1246 SPHERE - University of Nantes, Nantes, France; Véronique Sébille, PhD, ScD, Inserm U1246 SPHERE - University of Nantes, Nantes, France; Jean-Benoit Hardouin, PhD, ScD, Inserm U1246 SPHERE - University of Nantes, Nantes, France

2:26 pm – 2:43 pm (101.3) The statistical performances of common estimators for Minimal Clinically Important Difference determination of Patient-Reported Outcomes: a simulation study

Jean-Benoit Hardouin, INSERM UMR 1246-SPHERE “Methods: in Patients reported outcomes and HHealth ResEarch”, Nantes, France; Maxime Leroy, MSC, INSERM UMR 1246-SPHERE “Methods: in Patients reported outcomes and HHealth ResEarch”, Nantes, France; Antoine Vanier, PhD MD, INSERM UMR 1246-SPHERE “Methods: in Patients reported outcomes and HHealth ResEarch”, Nantes, France

2:44 pm – 3:01 pm (101.4) Evidence-based approach to determine meaningful change in scores of the EORTC QLQ-C30 in breast and head and neck cancer: on behalf of the EORTC Breast, Head and Neck and Quality of Life Groups

Jambe Z Musoro, PhD, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Corneel Coens, Msc, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Frederic Fiteni, MD PhD, University of Montpellier Montpellier, Montpellier, France; Katarzyna Pogoda, MD, Maria Skłodowska-Curie Institute - Oncology Center, Warsaw, Poland; Fatima Cardoso, MD, Champalimaud Clinical Centre, Champalimaud Foundation, Lisbon, Portugal; Nicola Russell, Netherlands Cancer Institute, Amsterdam, Netherlands; Susanne Singer, PhD, University of Leipzig, Leipzig, Germany; Christian Simon, MD, PhD, CHUV - Centre hospitalier universitaire vaudois, Lausanne, Switzerland; Jean-Pascal H. Machiels, MD, Department of Medical Oncology and Early drug Development, Cliniques Universitaires Saint-Luc, Brussels, Belgium; Silke Tribius, PD Dr. med., Department of Radiation Oncology, Asklepios Hospital St. Georg, Hamburg, Germany; Vincent Gregoire, MD, PhD, Cliniques Universitaires Saint-Luc, Brussels, Belgium; Sjoukje Oosting, Department of Medical Oncology, University Medical Center Groningen, Groningen, Netherlands; Galina Velikova, PhD, Leeds Institute of Cancer and Pathology/St James's Institute of Oncology, Leeds, United Kingdom; Mogens Groenvold, MD, PhD, University of Copenhagen, Copenhagen, Denmark; Madeleine T King, PhD, Psycho-Oncology Co-operative Research Group (PoCoG), University of Sydney, Sydney, Australia; Mirjam A.G. Sprangers, Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Andrew Bottomley, PhD, European Organisation for Research and Treatment of Cancer, Brussels, Belgium

Oral Session 102: Health Utilities

Meeting Room 6

Session Chair: David Feeny, PhD, Canada

1:50 pm – 2:07 pm (102.1) Development of health-state classification system for a new breast cancer-specific preference-based measure: the BREAST-Q-U

Manraj Kaur, McMaster University, Hamilton, Ontario, Canada; Andrea Pusic, MD MHS FACS FRCS, Harvard University, Boston, MA, United States; Feng Xie, PhD, McMaster University, Hamilton, Ontario, Canada; Louise Bordeleau, MD, MSc, FRCP(C), McMaster University, Hamilton, Ontario, Canada; Evan Matros, MD, MMSc, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Toni Zhong, MD, MHSc, FRCS, University of Toronto, Toronto, Ontario, Canada; Stefan Cano, PhD, CPsychol, AFBPsS, Modus Outcomes, Letchworth, United Kingdom; Susan Dimitry, BA, McMaster University, Hamilton, Ontario, Canada; Anne Klassen, BA, DPhil (Oxon), McMaster University, Hamilton, Ontario, Canada

2:08 pm – 2:25 pm (102.2) A hybrid modelling approach for eliciting Portuguese health states preferences

Patricia Antunes, CEISUC, Coimbra, Portugal; Pedro Lopes Ferreira, CEISUC, Coimbra, Portugal; Lara Noronha Ferreira, CEISUC, Coimbra, Portugal; Luís Pereira, CEISUC, Coimbra, Portugal

2:26 pm – 2:43 pm (102.3) Generating PROPr utility scores for the PROMIS-29

Barry Dewitt, PhD, Carnegie Mellon University, Pittsburgh, PA, United States; Hawre Jalal, MD, PhD, University of Pittsburgh, Pittsburgh, PA, United States; Janel Hanmer, MD, PhD, University of Pittsburgh, Pittsburgh, PA, United States

2:44 pm – 3:01 pm (102.4) Mind the (inter-rater) gap. An empirical investigation of self-reported and proxy reported quality of life in the derivation of childhood utility values for economic evaluation

Julie Ratcliffe, PhD Health Economics, Institute for Choice, Business School, University of South Australia, Adelaide, Australia; Jyoti Khadka, PhD, Institute for Choice, Business School, University of South Australia, Adelaide, Australia; Joseph Kwon, PhD, Warwick Medical School, University of Warwick, Coventry, United Kingdom; Stavros Petrou, PhD, Warwick Medical School, University of Warwick, Coventry, United Kingdom; Emily Lancsar, PhD, Department of Health Services Research and Policy, Research School of Population Health, The Australian National University, Canberra, Australia

Oral Session 103: Mobile Applications

Meeting Room 9

Session Chair: Lotte Haverman, PhD, Netherlands

1:50 pm – 2:07 pm (103.1) Qualitative interviews to explore experiences of using web-based and mobile technologies to support self-management of type 2 diabetes mellitus

Laura Kelly, University of Oxford, Oxford, United Kingdom; Crispin Jenkinson, University of Oxford, Oxford, United Kingdom; David Morley, University of Oxford, Oxford, United Kingdom

2:08 pm – 2:25 pm (103.2) Patients' experiences of using an interactive app during treatment for breast cancer

Maria Fjell, RN, OCN, PhD Candidate, Karolinska Institutet, Stockholm, Sweden; Ann Langius-Eklöf, RN, PhD, Professor, Karolinska Institutet, Stockholm, Sweden; Marie Nilsson, MSW, PhD, Karolinska Institutet, Stockholm, Sweden; Yvonne Wengström, RN, OCN, PhD, Professor, Karolinska Institutet, Stockholm, Sweden; Kay Sundberg, RN, PhD, Karolinska Institutet, Stockholm, Sweden

Scientific Program — Thursday, 25 October

2:26 pm – 2:43 pm (103.3) Routine use of patient reported symptoms assisted with an interactive app decreased symptom burden after surgery for pancreatic cancer

Tina Gustavell, Karolinska Institutet, NVS, Nursing, Stockholm, Sweden; Kay Sundberg, PhD, Karolinska Institutet, NVS, Nursing, Stockholm, Sweden; Ralf Segersvärd, PhD, Karolinska Institutet, CLINTEC, Surgery, Stockholm, Sweden; Yvonne Wengström, PhD, Karolinska Institutet, NVS, Nursing, Stockholm, Sweden; Ann Langius-Eklöf, PhD, Karolinska Institutet, NVS, Nursing, Stockholm, Sweden

2:44 pm – 3:01 pm (103.4) 'Kræftværket' - a co-created smartphone application to improve the quality of life of adolescents and young adults with cancer

Helle Pappot, MD, DMSc, senior consultant, Rigshospitalet, University Hospital of Copenhagen, Copenhagen, Denmark; Abbey Elsbernd, Medical student, University of Kansas, School of Medicine, Kansas City, KS, United States; Maiken Hjerding, Nurse specialist, Rigshospitalet, Copenhagen, Denmark; Camilla Visler, Nurse, Rigshospitalet, Copenhagen, Denmark; Lisa Lyngsie Hjalgrim, MD PhD, Rigshospitalet, Copenhagen, Denmark; Carsten U. Niemann, MD PhD, Rigshospitalet, Copenhagen, Denmark; Kirsten A. Boisen, MD PhD, Rigshospitalet, Copenhagen, Denmark

Oral Session 104: Holistic Measurement in Dementia and Alzheimer's Disease Pembroke & Herbert

Session Chair: Adam Gater, United Kingdom

1:50 pm – 2:07 pm (104.1) The conceptual relevance of assessment measures in patients with mild/mild-moderate Alzheimer's disease

Ann Hartry, Lundbeck, Deerfield, IL, United States; Natalie Aldhouse, DRG Abacus, Manchester, United Kingdom; Tamara Al-Zubeidi, DRG Abacus, Bicester, United Kingdom; Myrlene Sanon, Otsuka Pharmaceutical Development & Commercialization, Princeton, NJ, United States; Richard Stefanacci, Jefferson College of Population Health, Thomas Jefferson University, Philadelphia, PA, United States; Sarah Knight, DRG Abacus, Bicester, United Kingdom

2:08 pm – 2:25 pm (104.2) Exploring the responsiveness of Goal Attainment Scaling (GAS) in relation to number of goals set in a sample of patients with Alzheimer's Disease

Lisa McGarrigle, DGI Clinical, Halifax, Nova Scotia, Canada; Kenneth Rockwood, MD, DGI Clinical, Halifax, Nova Scotia, Canada

STUDENT ORAL PRESENTATION AWARD FINALIST

2:26 pm – 2:43 pm (104.3) Cross-cultural measurement of health-related quality of life in dementia: Secondary data analysis of UK and Latin American epidemiological samples

Jan R. Boehnke, School of Nursing and Health Sciences & Dundee Centre for Health and Related Research, University of Dundee, Dundee, United Kingdom; Kia-Chong Chua, Centre for Global Mental Health, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom; Martin Prince, King's Global Health Institute, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, United Kingdom; Sube Banerjee, Centre for Dementia Studies, Brighton and Sussex Medical School, University of Sussex, Brighton, United Kingdom

2:44 pm – 3:01 pm (104.4) Psychometric properties of DEMQOL and DEMQOL-Proxy in people with dementia: a Rasch based analysis

Jolijn Hendriks, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom; Sarah C. Smith, PhD, London School of Hygiene and Tropical Medicine, London, United Kingdom; Theopisti Chrysanthaki, PhD, University of Surrey, Guildford, United Kingdom; Nick Black, MD, London School of Hygiene and Tropical Medicine, London, United Kingdom

3:15 pm - 4:05 pm Exhibits Open and Refreshment Break Fitzwilliam Suites, Ground Floor

3:25 pm - 4:00 pm Thursday Poster Session II Lansdowne Room, Ground Floor

(1004) Quality of life as an outcome in EORTC clinical trials: 15 years of clinical trial research

Irina Ghislain, MSc, EORTC, Brussels, Belgium; Corneel Coens, MSc, EORTC, Brussels, Belgium; Madeline Pie, Ph.D, EORTC, Brussels, Belgium; Jaap C. Reijneveld, MD, VU University Medical Center, Amsterdam, Netherlands; Hans-Henning Flechtner, Ph.D, University of Magdeburg, Magdeburg, Germany; Eva Greimel, Ph.D, Medical University Graz, Graz, Austria; Andrew Bottomley, Ph.D, EORTC, Brussels, Belgium; submitted on behalf of EORTC

OUTSTANDING POSTER AWARD FINALIST

(1006) Reliability and validity of PROMIS Pediatric Family Relationships short form in children with chronic disease

Elizabeth Cox, MD, PhD, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States; Jennifer Connolly, MS, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States; Mari Palta, PhD, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States; Victoria Rajamanickam, MS, University of Wisconsin School of Medicine and Public Health, Madison, WI, United States; Kathryn Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

OUTSTANDING POSTER AWARD FINALIST

(1008) Down and out? Work and welfare trajectories among a cohort of Norwegian long-term social assistance recipients with complex health problems and low quality of life.

Borghild Løyland, Associate Professor, Oslo Metropolitan university, Oslo, Norway; Åsmund Hermansen, Associate professor, Oslo Metropolitan university, Oslo, Norway; Espen Dahl, Professor, Oslo Metropolitan university, Oslo, Norway; Kjetil van der Wel, Associate professor, Oslo Metropolitan university, Oslo, Norway; Magne Bråthen, Doctoral student, Oslo Metropolitan university, Oslo, Norway; Ivar Lødemel, Professor, Oslo Metropolitan university, Oslo, Norway; Astrid Klopstad Wahl, Professor, University of Oslo, Oslo, Norway

OUTSTANDING POSTER AWARD FINALIST

Cardiovascular

(1010) Developing a truly patient-derived outcome measure for cardiac procedures

Darshini Ayton, Monash University, Melbourne, Australia; Sze-Ee Soh, PhD, Monash University, Melbourne, Australia; Anna Barker, Medibank Private, Melbourne, Australia; Susannah Ahern, Monash University, Melbourne, Australia; Renata Morello, PhD, Monash University, Melbourne, Australia; Jeffrey Lefkowitz, Monash University, Melbourne, Australia; Angela Brennan, Monash University, Melbourne, Australia; Sue Evans, Monash University, Melbourne, Australia; John Zalberg, Monash University, Melbourne, Australia; Christopher Reid, Curtin University of Technology, Perth, Australia; Johannes Stoelwinder, Monash University, Melbourne, Australia; John McNeil, Monash University, Melbourne, Australia

(1012) Patient reported outcomes across stroke subtypes and TIA – Is there a difference?

Irene Katzan, MD, Cleveland Clinic, Cleveland, OH, United States; Andrew Schuster, BA, Cleveland Clinic, Cleveland, OH, United States; Christopher Newey, DO, Cleveland Clinic, Cleveland, OH, United States; Ken Uchino, MD, Cleveland Clinic, Cleveland, OH, United States; Brittany Lapin, PhD, Cleveland Clinic, Cleveland, OH, United States

(1014) Using Self-Reported Health-Related Quality of Life to Predict Incident Atherosclerotic Cardiovascular Disease Events

Laura Pinheiro, PhD, MPH, Weill Cornell Medicine, New York, NY, United States; Evgeniya Reshetnyak, PhD, Weill Cornell Medicine, New York, NY, United States; Madeline Sterling, MD, MPH, Weill Cornell Medicine, New York, NY, United States; Joshua Richman, MD, PhD, University of Alabama, Birmingham, AL, United States; Lisa Kern, MD, MPH, Weill Cornell Medicine, New York, NY, United States; Monika Safford, MD, Weill Cornell Medicine, New York, NY, United States

(1016) Patient-Reported Outcomes Predicts In-patient and Emergency Department Readmissions Risks in Acute Coronary Syndrome

Danielle A Southern, University of Calgary, Calgary, Alberta, Canada; **Meng Wang, University of Calgary, Calgary, Alberta, Canada;** Anita Brobbey, University of Calgary, Calgary, Alberta, Canada; Hude Quan, University of Calgary, Calgary, Alberta, Canada; Maria Santana, University of Calgary, Calgary, Alberta, Canada; Matthew T James, University of Calgary, Calgary, Alberta, Canada; Stephen B Wilton, University of Calgary, Calgary, Alberta, Canada; Oluwaseyi Lawal, University of Calgary, Calgary, Alberta, Canada; Oluwagbohunmi Awosoga, University of Lethbridge, Lethbridge, Alberta, Canada; Michelle M Graham, University of Alberta, Edmonton, Alberta, Canada; William A Ghali, University of Calgary, Calgary, Alberta, Canada; Lisa Lix, University of Manitoba, Winnipeg, Alberta, Canada; Merril L Knudtsen, University of Calgary, Calgary, Alberta, Canada; Colleen M Norris, University of Alberta, Edmonton, Alberta, Canada; Tolulope T Sajobi, University of Calgary, Calgary, Alberta, Canada

(1018) Evaluating the prognostic contribution of longitudinal patient reported outcomes in predicting mortality risk in acute coronary syndrome: a comparison of dynamic prediction models

Meng Wang, University of Calgary, Calgary, Alberta, Canada; Oluwaseyi Lawal, University of Calgary, Calgary, Alberta, Canada; Anita Brobbey, MSc, University of Calgary, Calgary, Alberta, Canada; Danielle Southern, MSc, University of Calgary, Calgary, Alberta, Canada; Stephen Wilton, MD, University of Calgary, Calgary, Alberta, Canada; Michelle Graham, MD, University of Alberta, Edmonton, Alberta, Canada; Maria Santana, PhD, University of Calgary, Calgary, Alberta, Canada; Oluwagbohunmi Awosoga, PhD, University of Lethbridge, Lethbridge, Alberta, Canada; Hude Quan, MD, PhD, University of Calgary, Calgary, Alberta, Canada; Matthew James, MD, PhD, University of Calgary, Calgary, Alberta, Canada; William Ghali, MD, MSc, University of Calgary, Calgary, Alberta, Canada; Colleen Norris, PhD, University of Alberta, Edmonton, Alberta, Canada; Lisa Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Merril Knudtsen, MD, University of Calgary, Calgary, Alberta, Canada; Tolulope Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada

(1020) Joint Modeling of Longitudinal Health-Related Quality of Life and All-Cause Mortality in Coronary Artery Disease

Oluwaseyi Lawal, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Meng Wang, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Danielle Southern, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Oluwagbohunmi Awosoga, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; **Maria Santana, Department of Community Health Sciences and Pediatrics, University of Calgary, Calgary, Alberta, Canada;** Stephen B. Wilton, Department of Community Health and Cardiac Sciences, University of Calgary, Calgary, Alberta, Canada; Matthew T. James, Department of Community Health and Cardiac Sciences, University of Calgary, Calgary, Alberta, Canada; Michelle M. Graham, Faculty of Medicine & Dentistry, University of Alberta, Edmonton, Alberta, Canada; Hude Quan, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; William A. Ghali, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Merril Knudtsen, Department of Cardiac Sciences, University of Calgary, Calgary, Alberta, Canada; Colleen M. Norris, Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada; Lisa M. Lix, Department of Community Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada; Tolulope Sajobi, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

E-health Implementation Studies

(1022) The Process of Capturing Patient-Reported Outcomes Electronically to Improve Dermatologic Care

Aaron Secrest, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD, MS, University of Utah, Salt Lake City, UT, United States

(1024) Bridging the gap between research and daily practice: optimization and implementation of mHeath tool PsyMate™ in primary care

Naomi Daniels, Maastricht University, Maastricht, Netherlands; Laura Hochstenbach, PhD, Zuyd University of applied Sciences, Heerlen, Netherlands; Marloes Bokhoven, PhD, MD, Maastricht University, Maastricht, Netherlands; Anna Beurskens, PhD, Prof, Zuyd University of applied Sciences, Heerlen, Netherlands; Philippe Delespaul, prof dr, Maastricht University, Maastricht, Netherlands

(1026) Exploring the Value of Real-Time Data Capture to Understand the Patient Experience of Hand Osteoarthritis

Sally Gatsi, GlaxoSmithKline, London, PA, United Kingdom; Rob Arbuckle, Adelphi Values, Manchester, United Kingdom; Pamela Berry, GlaxoSmithKline, Collegeville, PA, United States; Deven Chauhan, GlaxoSmithKline, London, PA, United Kingdom; Josephine Park, GlaxoSmithKline, Collegeville, PA, United States; Jane Wells, Adelphi Values, Manchester, PA, United Kingdom; Charlotte Panter, Adelphi Values, Manchester, United Kingdom

(1028) Stakeholder Perspectives on the Use of Patient-Generated Health Data to Transform Healthcare

Danielle Lavalley, University of Washington, Seattle, WA, United States; Elizabeth Austin, MPH, University of Washington, Seattle, WA, United States; Mara Nery-Hurwitz, PhD, University of Washington, Seattle, WA, United States; Jenney Lee, MA, University of Washington, Seattle, WA, United States; Richard Bloch, University of Washington, Seattle, WA, United States; Weni Chen, University of Washington, Seattle, WA, United States; Sarah Lawrence, MA, University of Washington, Seattle, WA, United States; Debbe McCall, University of Washington, Seattle, WA, United States; Sean Munson, PhD, University of Washington, Seattle, WA, United States; Dagmar Amtmann, PhD, University of Washington, Seattle, WA, United States

(1030) The role of sociodemographic factors in determining the uptake of electronic PROM completion in lung cancer patients: early indicators from the Life after lung cancer (LILAC) study.

Cecilia Pompili, MD, University of Leeds, Leeds, United Kingdom; Patricia Holch, Psychology Group, Leeds Beckett University, Leeds, United Kingdom; Emma Smyllie, University of Leeds, Leeds, United Kingdom; Hamza Mazhar, University of Leeds, Leeds, United Kingdom; Kate Absolom, University of Leeds, Leeds, United Kingdom; Kevin Franks, St James University Hospital, Leeds, United Kingdom; Galina Velikova, University of Leeds, Leeds, United Kingdom

(1032) Digital PRO data collection is a beneficial adjunct to patient self-management during recovery following abdominal cancer surgery: the eRAPID study

Hollie Richards, BSc MSc, University of Bristol, Bristol, United Kingdom; Kerry Avery, Dr, University of Bristol, Bristol, United Kingdom; Amanda Portal, University of Bristol, Bristol, United Kingdom; Trudy Reed, University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom; Ruth Harding, University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom; Robert Carter, University of Leeds, Leeds, United Kingdom; Kate Absolom, University of Leeds, Leeds, United Kingdom; Galina Velikova, Prof, University of Leeds, Leeds, United Kingdom; Jane Blazeby, Prof, University of Bristol, Bristol, United Kingdom

(1034) Withdrawn

(1036) Can pain drug development studies be improved using data from smartwatches?

Marie Mc Carthy, ICON Plc, Dublin, Ireland; Martin Geueke, PhD, ICON Plc, Dublin, Ireland; Peter Schueler, MD, ICON Drug Development Services CNS, Cologne, Germany; Willie Muehlhausen, DVM, ICON PLC, Dublin, Ireland

(1038) Lessons learned: key informant perspectives on successful implementation and administration of electronic tablet-based patient-reported outcome (PRO) measures in routine HIV care

Rob Fredericksen, University of Washington, Center for AIDS Research, Seattle, WA, United States; Anne Skalicky, MPH, Evidera, Seattle, WA, United States; Ethan Collins, MPH, Evidera, Seattle, WA, United States; Leah Kleinman, PhD, Evidera, Seattle, WA, United States; William Lober, MD MS, School of Nursing/ School of Medicine & School of Public Health, University of Washington, Seattle, WA, United States; Heidi Crane, MD, MPH, University of Washington, Center for AIDS Research, Seattle, WA, United States; Duncan Short, MSc, PhD, ViiV Healthcare, London, United Kingdom

(1040) Understanding the patient experience of presbyopia via a social media listening study

Claudia Leteneux-Pantais, Novartis Pharma AG, Basel, Switzerland; Daniel Viriato, Novartis Pharma AG, Basel, Switzerland; James Wolffsohn, Aston University, Birmingham, United Kingdom; Sarah Kilgariff, Adelphi Values Ltd, Bollington, United Kingdom; Jyothi Kommineni, Novartis Business Services, Hyderabad, India; Nishith Tyagi, Novartis Business Services, Hyderabad, India

Gastroenterology

(1042) Developing and Assessing A Scale of Ulcerative Colitis Reported by Clinician

Juelian Wang, first clinical medical school of Guangzhou University of Chinese Medicine, Guangzhou, China; Fengbin Liu, first clinical medical school of Guangzhou University of Chinese Medicine, Guangzhou, China; Zhengkun Hou, first clinical medical school of Guangzhou University of Chinese Medicine, Guangzhou, China

(1044) Evidence of Drug Treatment for Gastroesophageal Reflux Disease in China is good enough? An Overview of Systematic reviews/Meta analyzes

Zi-pan Lv, No.12 Airport Road Bai Yun Strict, Guangzhou, China; Zheng-kun Hou, No.12 Airport Road Bai Yun Strict, Guangzhou, China; Hai-qiang Ou, No.12 Airport Road Bai Yun Strict, Guangzhou, China; Xin-yuan Zhong, No.12 Airport Road Bai Yun Strict, Guangzhou, China; Feng-bin Liu, No.12 Airport Road Bai Yun Strict, Guangzhou, China

Low Socioeconomic Status

(1046) Unpacking the socioeconomic status and resilience connection: Reserve-building activities as mediators

Carolyn Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA, United States; Jie Zhang, M.P.H., DeltaQuest Foundation, Inc., Concord, MA, United States; Wesley Michael, M.B.A., Rare Patient Voice, LLC, Towson, MD, United States; Bruce Rapkin, Ph.D., Albert Einstein College of Medicine, Bronx, NY, United States

(1048) Health Effects of Late-Career Unemployment

Maren Voss, ScD, University of Utah, Salt Lake City, UT, United States; Beth Merryman, PhD, Towson University, Towson, MD, United States; Lisa Crabtree, PhD, Towson University, Towson, MD, United States; Wendy Birmingham, PhD, Brigham Young University, Provo, UT, United States; Lori Wadsworth, PhD, Brigham Young University, Provo, UT, United States; Man Hung, PhD, University of Utah, Salt Lake City, UT, United States

(1050) Quality of Life Measures for People with Hypertension Living in a Poor, Rural Community

Nalin Payakachat, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; J Mick Tilford, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; James Seliq, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; Martha Phillips, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

(1052) Comparison of pre-injury recalled health-related quality of life (HRQoL) data of trauma patients and HRQoL of the general population: can educational level explain the difference?

Nena Kruihof, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Juanita Haagsma, Erasmus MC University Medical Centre, Department of Public Health, Rotterdam, the Netherlands, Rotterdam, Netherlands; Leonie de Munter, ETZ Hospital (Elisabeth-TweeSteden Ziekenhuis), Department Trauma TopCare, Tilburg, the Netherlands, Tilburg, Netherlands; Suzanne Polinder, Erasmus MC University Medical Centre, Department of Public Health, Rotterdam, the Netherlands, Rotterdam, Netherlands; Mariska de Jongh, Brabant Trauma Registry, Network Emergency Care Brabant, Tilburg, the Netherlands, Tilburg, Netherlands

Patient Education and Health Promotion

(1054) Investigating the Health-promoting Behaviors and the Predictive Factors Among the Employees of Tehran Tobacco Company

Farahnaz Khajehnasiri, PhD, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Soheila Dabiran, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Shahlla Khosravi, Department of community Medicine, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran; Elham Hokmabadi, School of Medicine, Tehran University of Medical Sciences, Tehran, Iran

(1056) Health literacy across all year levels of a cohort of Australian osteopathy students

Jane Mulcahy, Victoria University, Melbourne, Australia; Brett Vaughan, MHS, BSc, University of Melbourne, Melbourne, Australia

(1058) Shared Medical Appointments Improve Quality of Life for Patients with Atrial Fibrillation

Joan Griffin, PhD, Mayo Clinic-Rochester, Rochester, MN, United States; Monika Schmidt, D.N.P., APRN, AGNP-C, Mayo Clinic-Rochester, Rochester, MN, United States; Lynette Stuart-Mullen, M.S.N., APRN, C.N.S., Mayo Clinic-Rochester, Rochester, MN, United States; Pamela McCabe, Ph.D., APRN, CNS, Mayo Clinic-Rochester, Rochester, MN, United States; Megan Branda, MS, Mayo Clinic-Rochester, Rochester, MN, United States; Thomas O Byrne, BS, Mayo Clinic-Rochester, Rochester, MN, United States; Christopher McLeod, MBChB, Ph.D., FHRS, Mayo Clinic-Jacksonville, Rochester, MN, United States

(1060) Physical activity level, self-efficacy and perceived health status in Brazilian patients before undergoing the first percutaneous coronary intervention

Lidia A. Rossi, University of São Paulo, Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Natássia C. Pitta, Physiotherapist, PhD. student, University of São Paulo, Ribeirão Preto College of Nursing, Ribeirão Preto-SP, Brazil; Rosana A. S. Dantas, RN, PhD, Professor, University of São Paulo, Ribeirão Preto College of Nursing, Ribeirão Preto-SP, Brazil; Márcia A. Ciol, Research Professor, Department of Rehabilitation Medicine, School of Medicine, University of Washington, USA, Seattle, WA, United States

(1062) Development of a patient education program for patients undergoing body contouring after massive weight loss

Lotte Poulsen, MD, Department of Plastic Surgery, Odense University Hospital, Odense, Denmark; Signe Poulsen, Nurse, Department of Plastic Surgery, Odense, Ontario, Denmark; Birgitta Fahnoe Larsen, nurse, Department of Plastic Surgery, Odense University Hospital, Odense, Denmark; Mike Lorenzen, Medical student, Department of Plastic Surgery, Odense University Hospital, Odense, Denmark; Kirsten K Roessler, DPhil, PhD, Department of Psychology, University of Southern Denmark, Odense, Denmark; Joern Bo Thomsen, MD, PhD, Department of Plastic Surgery, Odense University Hospital, Odense, Denmark; Michael Rose, MD, Department of Plastic Surgery, Hospital of Southwest Jutland, Esbjerg, Denmark; Anne Klassen, DPhil, PhD, Department of Pediatrics, McMaster University, Hamilton, Ontario, Canada; Jens Ahm Sorensen, MD, PhD, Department of Plastic Surgery, Odense University Hospital, Odense, Denmark

(1064) Effect of mat Pilates versus walking on quality of life of women with abdominal obesity, insulin resistance, and NAFLD

Maria Dida Silva Pestana, Universidade Estadual do Sudoeste da Bahia, Ipiaú, Brazil; Valnei Luciano Pereira Pestana, Médico, EsP, Secretaria de Saúde do Estado da Bahia, Ipiaú, Bahia, Brazil; Vitor Silva Pestana, Fisioterapeuta, MSc, Universidade Federal da Bahia, Salvador, Bahia, Brazil; Manuella Castro Silva Pestana, Fisioterapeuta, MSc, Universidade Federal da Bahia, Salvador, Bahia, Brazil; Marcelo Costa Silva, Médico, PhD, Secretaria de Saúde do Estado da Bahia, Ipiaú, Bahia, Brazil; Maria Isabel Schinoni, Médica, PhD, Universidade Federal da Bahia, Salvador, Bahia, Brazil

(1066) Focus groups with psoriasis-patients for the development of a standard dataset for the documentation of psoriasis

Marina Otten, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Augustin, Prof. Dr., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(1068) A survey of public knowledge and attitude related to antibiotics use and resistance in southwest Alberta, Canada

Oyindamola Jaja, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Monique Sedgwick, PhD, Nursing, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Darren Christensen, PhD, Addictions Counselling, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Oluwaseyi Lawal, MSc, University of Calgary, Calgary, Alberta, Canada; Tolulope Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; **Oluwagbohunmi Awosoga, PhD, MBA, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada**

(1070) Health-related quality of life of patients using warfarin: a randomized controlled trial of the effect of telephone encouragement for the management of oral anticoagulation therapy

Rafaela Manzato, PhD student, University of São Paulo, Ribeirão Preto, Brazil; Débora Cunha, PhD Student, University of São Paulo, Ribeirão Preto, Brazil; Eliane Nepomuceno, PhD Student, University of São Paulo, Ribeirão Preto, Brazil; Fabiana Bolela, PhD, University of São Paulo, Ribeirão Preto, Brazil; Rejane Furuya, PhD, University of São Paulo, Ribeirão Preto, Brazil; Carina Dessotte, PhD, University of São Paulo, Ribeirão Preto, Brazil; Márcia Ciol, PhD, University of Washington, Seattle, WA, United States; **Rosana Dantas, PhD, University of São Paulo, Ribeirão Preto, Brazil**

PROs in Clinical Practice

(1072) Clinical Application and Usage of Patient Reported Outcome Measures in an Orthopaedic Outpatient Setting

Amanda Spraggs-Hughes, Washington University School of Medicine, St. Louis, MO, United States; Jason Guattery, MS, Washington University School of Medicine, St. Louis, MO, United States; Ryan Calfee, MD, MSc, Washington University School of Medicine, St. Louis, MO, United States

(1074) How often do PROMs trigger a concerning symptom alert in a cancer trial and what actions do nurses take?: Early results from a cluster-randomized trial examining electronic patient reporting of symptoms between visits (AFT-39)

Angela Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Sydney Henson, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Phillip Carr, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Jennifer Jansen, MPH, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Antonia Bennett, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Mattias Jonsson, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Claire Snyder, PhD, Johns Hopkins University, Baltimore, MD, United States; Deborah Schrag, MD, MPH, Harvard University, Boston, MA, United States; Jane Perlmutter, PhD, MBA, Gemini Patient Advocacy Group, Ann Arbor, MI, United States; Mary Lou Smith, JD, MBA, Research Advocacy Network, Naperville, IL, United States; Patricia Spears, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Ethan Basch, MD, MSc, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

(1076) Understanding the barriers and facilitators to implementing patient-reported outcome measures in surgery.

Chris Gibbons, Brigham and Women's Hospital / Harvard Medical School, Boston, United States; Elena Tsengaris, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States; Laura Dominici, Brigham and Women's Hospital / Dana-Farber Cancer Center, Boston, MA, United States; Andrea Pusic, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States

(1078) Using Patient Experience (UsPex): results of a national survey of Patient Experience Leads

Elizabeth Gibbons, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom; Jenny King, MSc, Picker Institute Europe, Oxford, United Kingdom; Louise Locock, PhD, Health Services Research Unit, University of Aberdeen, Aberdeen, United Kingdom

(1080) A survey of Patient Reported Outcome Measures (PROMs) used in General Practice in England

Grace Turner, PhD, University of Birmingham, Birmingham, United Kingdom; Sam Finnikin, MRCP, MBChB, DRCOG, MSc, MA (cantab), University of Birmingham, Birmingham, United Kingdom; Derek Kyte, PhD, University of Birmingham, Birmingham, United Kingdom; Clare Taylor, MBE, MA, MPH, PhD, FRCGP, University of Oxford, Oxford, United Kingdom; Helen Stokes-Lampard, MBBS (Lon), PhD, FRCGP, DFSRH, DRCOG, LOC(IUS), Royal College of General Practitioners, London, United Kingdom; Melanie Calvert, PhD, University of Birmingham, Birmingham, United Kingdom

(1082) Implementing the KLIK PROM tool in clinical care; the healthcare professional's point of view.

Hedy van Oers, MSc, Psychosocial department, Emma Children's Hospital AMC, Amsterdam, Netherlands; Lorynn Teela, MSc, Psychosocial department, Emma Children's Hospital AMC, Amsterdam, Netherlands; Maud van Muilekom, MSc, Psychosocial department, Emma Children's Hospital AMC, Amsterdam, Netherlands; Martha Grootenhuis, PhD, Psychosocial department, Emma Children's Hospital AMC, Amsterdam, Netherlands; Lotte Haverman, PhD, Psychosocial department, Emma Children's Hospital AMC, Amsterdam, Netherlands

(1084) Lessons Learned and Future Directions for Patient Reported Outcome Usage at an Academic Medical Center

Jason Guattery, Washington University School of Medicine, St. Louis, MO, United States; Amanda Spraggs-Hughes, MA, Washington University School of Medicine, St. Louis, MO, United States; Ryan Calfee, MD, MSc, Washington University School of Medicine, St. Louis, MO, United States

(1086) Systematic Review of the Use of Patient Reported Outcome Measures in Studies of Electively-Managed Hand Conditions

Luke Geoghegan, BSc, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom; Hawys Lloyd-Hughes, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom; Michelle Peters, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom; Andrew Price, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom; David Beard, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom; Abhilash Jain, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom; **Jeremy Rodrigues, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Science (NDORMS), University of Oxford, Oxford, United Kingdom**

(1088) Development of a Patient Reported Measure of Quality of Care Transitions: Evidence of Structural Validity

Milena Anatchkova, Evidera, Waltham, MA, United States; Mark Atkinson, Evidera, Seattle, OR, United States; Heena Santry, Ohio State University Wexner Medical Center, Columbus, OH, United States; Nathaniel Erskine, University of Massachusetts Medical School, Worcester, MA, United States; Catarina Kiefe, University of Massachusetts Medical School, Worcester, MA, United States

(1090) The use of Patient-Reported Outcome Measures (PROMs) in patients with End Stage Renal Disease requiring treatment with Haemodialysis (HD): a narrative review.

Nicola Anderson, BA, MSc, University of Birmingham, Birmingham, United Kingdom; Melanie Calvert, PhD, University of Birmingham, Birmingham, United Kingdom; Mary Dutton, MSc, University Hospitals Birmingham NHS Foundation Trust, Birmingham, United Kingdom; Paul Cockwell, PhD, University Hospitals Birmingham NHS Foundation Trust, Birmingham, United Kingdom; Derek Kyte, PhD, University of Birmingham, Birmingham, United Kingdom

(1092) A qualitative study of patients' and clinicians' perspectives on the use of electronic patient-reported outcome measures (ePROMs) in the management of patients with advanced chronic kidney disease (PRO-track project)

Olaekan Lee Aiyegbusi, MBChB, MPH, Centre for Patient-Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Derek Kyte, PhD, Centre for Patient-Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Paul Cockwell, MB.BCh, PhD, Department of Renal Medicine, University Hospitals Birmingham NHS Foundation Trust, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Tom Marshall, MBChB, PhD, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Stephanie Stringer, MBChB, PhD, Department of Renal Medicine, University Hospitals Birmingham NHS Foundation Trust, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Mary Dutton, RN, Department of Renal Medicine, University Hospitals Birmingham NHS Foundation Trust, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Natalie Walmsley-Allen, RN, Department of Renal Medicine, University Hospitals Birmingham NHS Foundation Trust, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Anita Slade, PhD, Centre for Patient Reported Outcomes Research (CPROR), Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Christel McMullan, PhD, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Melanie Calvert, PhD, Centre for Patient-Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom

(1094) Development and Psychometric Validation of a Mini Quality of Life Assessment Tool for Use in Routine Oncology Practice

Revathy Krishnamurthy, MBBS MD Radiation Oncology, Tata Memorial Centre, Mumbai, India; Mansi Munshi, MBBS MD Radiation Oncology, Tata Memorial Centre, Mumbai, India; Akshay Mangaj, MBBS, Tata Memorial Centre, Mumbai, India; Santam Chakraborty, MBBS MD Radiation Oncology, Tata Memorial Centre, Mumbai, India; Rajiv Sarin, MBBS MD Radiation Oncology FRCR Clinical Oncology, Tata Memorial Centre, Mumbai, India

(1096) Withdrawn

(1098) Identifying Areas for Improvement in Pediatric Inpatient Care Through the Child HCAHPS Survey

Sadia Ahmed, Bachelor of Health Sciences, University of Calgary, Calgary, Alberta, Canada; Kyle Kemp, MSc, University of Calgary, Calgary, Alberta, Canada; David Johnson, MD, Alberta Children's Hospital, Calgary, Alberta, Canada; Hude Quan, PhD, University of Calgary, Calgary, Alberta, Canada; Maria Santana, PhD, University of Calgary, Calgary, Alberta, Canada

(1100) Integrating PROs into Chronic Care Improves Communication, Satisfaction, and Confidence in Decision-Making in Patients and Physicians

Susan Bartlett, McGill University, Montreal, Quebec, Canada; Elaine de Leon, Johns Hopkins Medicine, Baltimore, MD, United States; Trisha Duncan, Johns Hopkins Medicine, Baltimore, MD, United States; Ana Maria Orbai, Johns Hopkins Medicine, Baltimore, MD, United States; Victoria Ruffing, Johns Hopkins Medicine, Baltimore, MD, United States; Alessandra Butanis, Johns Hopkins Medicine, Baltimore, MD, United States; Michelle Jones, Johns Hopkins Medicine, Baltimore, MD, United States; Amye Leong, Healthy Motivation, Santa Barbara, MD, United States; Clifton Bingham, MD, Johns Hopkins Medicine, Baltimore, MD, United States

Public Health

(1102) A comparison of comorbidity indices based on health-related quality of life and mortality for predicting medical expenditures

Avery A. Rizio, Optum, Johnston, RI, United States; Kristen L. McCausland, MPH, PhD, Optum, Johnston, RI, United States; Regina Rendas-Baum, MS, Optum, Johnston, RI, United States

(1104) Withdrawn

(1106) Development of a new outcome measure to assess the impact of reduced-risk tobacco- and nicotine-containing products on health and functioning: a comprehensive literature search

Erica Spies, PhD, MS, BA, PMI, Neuchatel, Switzerland; Linda Abetz-Webb, Patient-Centered Outcomes Assessment, Cheshire, United Kingdom; Sophie Gallot, PMI, Neuchatel, Switzerland; Esther Afolalu, PMI, Neuchatel, Switzerland; Christelle Chrea, PMI, Neuchatel, Switzerland; Rolf Weitkunat, PMI, Neuchatel, Switzerland

(1108) Development and validation of a questionnaire to evaluate psycho-social occupational hazards of subjects who work in confined spaces.

Monica Mombelli, Master, Centro Universitário União Dinâmica das Cataratas, Foz do Iguaçu, Brazil; Valeria Andrade, Master, Federal University of Triângulo Mineiro, Uberaba, Brazil; Viviane Romeiro, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Beatriz Conacci, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Fernanda Karla Nascimento, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; **Claudia Benedita dos Santos, Doctor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil**

(1110) Development and initial validation of a health-related quality of life instrument for Chinese patients with chronic hepatitis B(CHBQOL)

Lin Zhu, Zhejiang University School of Medicine, Hangzhou, China; Mengna Song, Zhejiang University School of Medicine, Hangzhou, China; Xiao Cheng, Zhejiang University School of Medicine, Hangzhou, China; Yingjing Zheng, Zhejiang University School of Medicine, Hangzhou, China; Li Zhang, Zhejiang University School of Medicine, Hangzhou, China; **Hongmei Wang, PhD, Zhejiang University School of Public Health, Hangzhou, China**

(1112) Compression of morbidity revisited: Data from the Global Burden of Disease study

Jacek Kopec, University of British Columbia, Vancouver, British Columbia, Canada

(1114) Identifying people with disability in health system and service data sets

Janet Sansoni, Bachelor of Arts, Master of Science, Diploma of Education, Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia; Pam Grootemaat, Bachelor of Science, Master of Public Health, Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia; Anita Westera, Bachelor of Arts (Hons), Registered Nurse, Graduate Certificate Health Services Research and Development, Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia; David Fildes, Bachelor of Arts, Master of Public Health, Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia; Darcy Morris, Bachelor of Arts, Graduate Certificate in Health Services Research and Development, Australian Health Services Research Institute, University of Wollongong, Wollongong, Australia

(1116) A snapshot of quality of life research in medicine and health research

Kristin Haraldstad, PhD, University of Agder, Kristiansand, Norway; Astrid Wahl, Professor, University of Oslo, Oslo, Norway; Marit Andersen, OUS, Oslo, Norway; Randi Andenæs, OsloMET, Oslo, Norway; Christine Råheim Borge, UiO, Oslo, Norway; Eivind Engebretsen, UiO, Oslo, Norway; Martin Eiseman, UiT, Tromsø, Norway; Elisabeth Beisland, HiB, Bergen, Norway; John Roger Andersen, hisf, Førde, Norway; Lisbeth Gravdal Kvarme, OsloMET, Oslo, Norway; Anne Haugstvedt, HiB, Bergen, Norway; Liv Halvorsrud, OsloMET, Oslo, Norway; Tove A Hansen, UNN, Tromsø, Norway; Trude Haugland, diakonova, Oslo, Norway; Venke Johansen, Helse-Bergen, Bergen, Norway; Tone M Norekvål, Helse-Bergen, UiB, Bergen, Norway; Borghild Løyland, OsloMET, Oslo, Norway; Marie Marie Hamilton Larsen, UiO, Oslo, Norway; Kristin Hjorthaug Urstad, UiS, Stavanger, Norway; Lis Ribbu, OsloMET, Oslo, Norway; Lise Løvereide, SUS, Stavanger, Norway; Gudrun Rohde, UiA, Kristiansand, Norway; Solvi Helseth, OsloMet, Oslo, Norway

(1118) Withdrawn

(1120) The effect of implementation a program the physical activity in the functionality and Quality of Life in old people

Luisa Pedro, Estesl - IPL, Lisboa, Portugal; José Pais Ribeiro, Professor, FPCE- UP, Porto, Portugal; João Pascoa Pinheiro, Professor, FM-UC, Coimbra, Portugal

(1122) Withdrawn

Registries

(1124) Auxiliary Information in Multiple Imputation Models: Effects on Estimated Change in Patient-Reported Outcomes from Clinical Registry Data

Olawale Ayilara, University of Manitoba, Winnipeg, Manitoba, Canada; Eric Bohm, University of Manitoba, Winnipeg, Manitoba, Canada; Lin Yan, University of Manitoba, Winnipeg, Manitoba, Canada; Tolulope Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Richard Sawatzky, PhD, Trinity Western University, Vancouver, British Columbia, Canada; **Lisa Lix, University of Manitoba, Winnipeg, Manitoba, Canada**

(1126) Complementing clinical cancer registries with patient-reported outcome data – A feasibility study on routine ePRO assessment for the Austrian Myeloma Registry

Monika Sztankay, Medical University of Innsbruck, University Hospital Innsbruck, Innsbruck, Austria; Lucia Neppi, MSc, Oncotryol - Center for Personalized Cancer Medicine, Innsbruck, Austria; Lisa Wintner, MSc, Department of Psychiatry, Psychotherapy & Psychosomatics, Medical University of Innsbruck, Innsbruck, Austria; Gerhard Rumpold, Assoc. Prof., Department of Medical Psychology, Innsbruck, Austria; Roman Weger, MSc, Oncotryol - Center for Personalized Cancer Medicine, Innsbruck, Austria; Wolfgang Willenbacher, MD, Department of Internal Medicine V, Haematology/Oncology, Medical University of Innsbruck, Innsbruck, Austria; Walpurga Weyrer, MD, Department of Internal Medicine V, Haematology/Oncology, Medical University of Innsbruck, Innsbruck, Austria; Michael Steurer, Prof., Department of Internal Medicine V, Haematology/Oncology, Medical University of Innsbruck, Innsbruck, Austria; Bernhard Holzner, Prof., Department of Psychiatry, Psychotherapy & Psychosomatics, Medical University of Innsbruck, Innsbruck, Austria

(1128) Developing guidelines for PROs inclusion to clinical quality registries

Rasa Ruseckaite, Monash University, Melbourne, Australia; Joanne Dean, Monash University, Melbourne, Australia; Sue Evans, Monash University, Melbourne, Australia; Belinda Gabbe, Monash University, Melbourne, Australia; Susannah Ahern, Monash University, Melbourne, Australia

(1130) Cancer Survivor Viewpoints on Sharing Patient Generated Health Data with Central Cancer Registries

Tenbroeck Smith, MA, American Cancer Society, Atlanta, GA, United States; Neil Aaronson, Netherlands Cancer Institute, Amsterdam, Netherlands; Kerry Levin, Westat, Rockville, MD, United States; Sophia Tsakraklides, Westat, Rockville, MD, United States; Lonke van de Poll-Franse, Netherlands Cancer Institute, Amsterdam, Netherlands; Marsha Dunn, Westat, Rockville, MD, United States; Xiao-Cheng Wu, Louisiana Tumor Registry, New Orleans, LA, United States; Charles Wiggins, New Mexico Tumor Registry, Albuquerque, NM, United States; Kevin Ward, Emory University, Atlanta, GA, United States; Sandra Mitchell, National Cancer Institute, Bethesda, MD, United States; Marc Hurlbert, Metastatic Breast Cancer Alliance, New York, NY, United States; Lynne Penberthy, National Cancer Institute, Bethesda, MD, United States

(1132) Infrastructure and early response rates for a national, prospective collection of Patient Reported Outcome Measures (PROMs) from prostate cancer (PCa) patients and controls

Ylva Gjelsvik, MA, Cancer Registry of Norway, Oslo, Norway; Tor Åge Myklebust, PhD, Cancer Registry of Norway, Oslo, Norway; Sophie Dorothea Fosså, MD, PhD, Oslo University Hospital, Oslo, Norway; Erik Skaheim Haug, MD, PhD, Vestfold Hospital, Tønsberg, Norway; Rune Kvåle, MD, PhD, Haukeland University Hospital, Department of Oncology and Medical Physics, Bergen, Norway; Marjolein Memelink Iversen, PhD, Centre on patient reported outcomes data, Haukeland University Hospital, Bergen, Norway; Jan Franz Nygård, PhD, Cancer Registry of Norway, Oslo, Norway; Kristin Hoel Brenden, MA, Cancer Registry of Norway, Oslo, Norway; Giske Ursin, MD, Cancer Registry of Norway, Oslo, Norway; Tom Børge Johannesen, MD, PhD, Cancer Registry of Norway, Oslo, Norway

(1134) Patient and Public Involvement Questionnaire (PPIQ), preliminary sensibility testing results

Zahava Rosenberg-Yunger, PhD, Ryerson University, Toronto, Ontario, Canada; Lee Verweel, MSc, West Park HealthCare Centre, Toronto, Ontario, Canada

4:05 pm – 5:35 pm Concurrent Oral Sessions

Oral Session 105: Paediatrics Meeting Room 1+2, Second Floor

Session Chair: Rob Arbuckle, United Kingdom

4:10 pm – 4:27 pm (105.1) Do children/adolescents with chronic health conditions have worse HrQoL than their healthy peers? A meta-analysis of studies using the KIDSCREEN questionnaires

Neuza Silva, PhD, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Marco Pereira, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Christiane Otto, Department of Child and Adolescent Psychiatry and Psychotherapy, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ulrike Ravens-Sieberer, Department of Child and Adolescent Psychiatry and Psychotherapy, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Maria Cristina Canavarro, Centre for Research in Neuropsychology and Cognitive Behavioural Intervention (CINEICC), Faculty of Psychology and Education Sciences of the University of Coimbra, Coimbra, Portugal; Monika Bullinger, Department of Medical Psychology, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

4:28 pm – 4:45 pm (105.2) Trajectories of Health-Related Quality of Life and Mental Wellbeing in Children and Adolescents: Results of the BELLA Cohort Study

Ulrike Ravens-Sieberer, Prof. Dr. phil, MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Claus Barkmann, Dr. phil. Dipl.-Psych., MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Christiane Otto, Dr. rer. hum. biol. Dipl.-Psych., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ann-Katrin Meyrose, M. Sc.-Psych., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Franz Petermann, Prof. Dr., University of Bremen, Bremen, Germany; Robert Schlack, Dr. rer. nat., Robert Koch Institute, Berlin, Germany; Monika Bullinger, Prof. Dr. phil. Dipl.-Psych., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Michael Schulte-Markwort, Univ.-Prof. Dr. med., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klasen, Priv.-Doz. Dr. phil. Dipl.-Psych., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

4:46 pm – 5:03 pm (105.3) Health-related quality of life of Dutch children and adolescents with a chronic health condition aged 6 to 18 years

Maud van Muilekom, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Hedy van Oers, MSc, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Michiel Luijten, MSc, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Thirsa Conijn, MSc, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Heleen Maurice-Stam, PhD, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Martha Grootenhuys, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Lotte Haverman, PhD, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands

5:04 pm – 5:21 pm (105.4) Quality of Life (QOL) of typically developing children depends on how old they are and where they live: A meta-analysis with meta-regression

Nikki Ow, McGill University, Montreal, Quebec, Canada; Nancy E. Mayo, McGill University, Montreal, Quebec, Canada

Session Chair: Galina Velikova, MD, PhD, FRCP, United Kingdom

4:10 pm – 4:27 pm (106.1) Translation and Linguistic Validation of the US National Cancer Institute's Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE™) in 10 Languages

Sandra Mitchell, PhD, CRNP, FAAN, National Cancer Institute, Rockville, MD, United States; Elizabeth Yohe Moore, MPH, RWS Life Sciences, East Hartford, CT, United States; Shawn McKown, MA, RWS Life Sciences, East Hartford, CT, United States; Timothy Poepsel, PhD, RWS Life Sciences, East Hartford, CT, United States; Matthew Lauritzen, BA, RWS Life Sciences, East Hartford, CT, United States; Alicyn Campbell, MPH, Genentech-A Member of the Roche Group, South San Francisco CA, United States; Elisabeth Pialut, PharmD, Genentech-A Member of the Roche Group, South San Francisco, CA, United States; Katherine Zarzar, BA, Genentech-A Member of the Roche Group, South San Francisco, CA, United States; Katherine Kim, MPH, Genentech-A Member of the Roche Group, South San Francisco, CA, United States

4:28 pm – 4:45 pm (106.2) The Electronic Collection of Patient-Reported Outcomes (PROs) to Assess Symptom Burden After Ambulatory Cancer Surgery

Cara Stable, MPH, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Andrea Pusic, MD, MHS, FACS, FRCSC, Brigham and Women's Hospital, Boston, MA, United States; Brett Simon, MD, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Daniel Stein, MD, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Peter Stetson, MD, MA, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Rori Salvaggio, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Andrew Vickers, PhD, Memorial Sloan Kettering Cancer Center, New York NY, United States; Magalie Lilavois, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Vincent Laudone, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Rebecca Twersky, MD, MPH, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Marcia Levine, MSN, RN, NE-BC, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Jeanne Carter, PhD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Amylou Dueck, PhD, Mayo Clinic, Rochester, MN, United States; Ethan Basch, MD, MSc, University of North Carolina, Chapel Hill, NC, United States; Larissa Temple, MD, University of Rochester, Rochester, NY, United States

4:46 pm – 5:03 pm (106.3) Floor & ceiling effects in physical functioning as measured by the EORTC QLQ-C30 in breast cancer patients

Bellinda King-Kallimanis, US FDA, Silver Spring, MD, United States; Lynn Howie, US FDA, Silver Spring, MD, United States; Jennifer Gao, US FDA, Silver Spring, MD, United States; Selena Daniels, US FDA, Silver Spring, MD, United States; Hui Zhang, US FDA, Silver Spring, MD, United States; Julia Beaver, US FDA, Silver Spring, MD, United States; Paul Kluetz, US FDA, Silver Spring MD, United States

5:04 pm – 5:21 pm (106.4) Establishing the European Norm for the health-related quality of life scales of the EORTC Computer-Adaptive Test and new reference values for the QLQ-C30 based on a population survey of 15,386 persons across 13 European countries, the USA, and Canada

Sandra Nolte, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Berlin, Germany; Gregor Liegl, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Berlin, Germany; Morten Aa Petersen, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark; Neil Aaronson, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Anna Costantini, Psycho-Oncology Unit, Sant'Andrea Hospital Sapienza, University of Rome, Rome, Italy; Peter Fayes, Institute of Applied Health Science, University of Aberdeen, Aberdeen, United Kingdom; Mogens Groenvold, Department of Palliative Medicine, Bispebjerg Hospital, Copenhagen, Denmark; Bernhard Holzner, Department of Psychiatry and Psychotherapy, Medical University Innsbruck, Innsbruck, Austria; Colin D Johnson, Professor of Surgical Sciences, University of Southampton, Southampton, United Kingdom; Georg Kemmler, Department of Psychiatry and Psychotherapy, Medical University Innsbruck, Innsbruck, Austria; Krzysztof Tomaszewski, Department of Orthopaedic Surgery, 5th Military Clinical Hospital, Krakow, Poland; and Department of Anatomy, Jagiellonian University Medical College, Krakow, Poland; Annika Waldmann, Ministry for Health and Consumer Protection, Hamburg Cancer Registry, Hamburg, Germany; Teresa Young, Lynda Jackson Macmillan Centre, Mount Vernon Hospital, Middlesex, United Kingdom; Matthias Rose, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Berlin, Germany; submitted on behalf of EORTC Quality of Life Group

Oral Session 107: Mapping and Linking Across Measures

Meeting Room 9, Second Floor

Session Chair: Karon F. Cook, PhD, United States

4:10 pm – 4:27 pm (107.1) Mapping PROMIS Physical Function Scores to Functional Ability

Joshua Biber, MS, MBA, University of Utah Health, Salt Lake City, UT, United States; Howard Weeks, MD, University of Utah Health, Salt Lake City, UT, United States; Craig Gale, MS, University of Utah Health, Salt Lake City, UT, United States; Heidi Cozart, University of Utah Health, Salt Lake City, UT, United States; Darrel Brodke, MD, University of Utah Health, Salt Lake City, UT, United States; Anne Thackeray, PhD, University of Utah Health, Salt Lake City, UT, United States; Rachel Hess, MD, MS, University of Utah Health, Salt Lake City, UT, United States

STUDENT ORAL PRESENTATION AWARD FINALIST

4:28 pm – 4:45 pm (107.2) Linking multiple versions of the Perceived Stress Scale with NIH Toolbox

Benjamin Schalet, Northwestern University Feinberg School of Medicine, Evanston, IL, United States; James Griffith, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; John Salsman, Wake Forest School of Medicine, Winston-Salem, NC, United States; Cindy Nowinski, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Richard Gershon, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; David Cella, Northwestern University Feinberg School of Medicine, Chicago, IL, United States

4:46 pm – 5:03 pm (107.3) Can We Get There from Here? Linking Scores of Legacy Depression Measures to PROMIS-Depression in the Absence of Co-administration.

Michael Kallen, PhD, MPH, Northwestern University, Missouri City, TX, United States; Karon Cook, PhD, Northwestern University, Houston, TX, United States; Richard Gershon, PhD, Northwestern University, Chicago, IL, United States; Dagmar Amtmann, PhD, University of Washington, Seattle, WA, United States; David Cella, PhD, Northwestern University, Chicago, IL, United States

5:04 pm – 5:21 pm (107.4) An Algorithm to generate EQ-5D-5L Utility Scores from the Dermatology Life Quality Index: A Direct Mapping Study in a Population with Atopic Dermatitis

Andreas Viilsbøll, Aalborg University, Aalborg, Denmark; Nana Kragh, MSc Econ, LEO Pharma, Copenhagen, Denmark; Julie Hahn-Pedersen, Cand. Scient. Med., LEO Pharma, Copenhagen, Denmark; Cathrine Elgaard Jensen, Cand. Scient. Med, Aalborg University, Aalborg, Denmark

Oral Session 108: Digital Health Technologies

Meeting Room 6, Second Floor

Session Chair: Roxanne Jensen, PhD, United States

4:10 pm – 4:27 pm (108.1) Social media use and happiness with aspects of life in young people

Philip Powell, PhD, University of Sheffield, Sheffield, United Kingdom; Emily McDool, PhD, University of Sheffield, Sheffield, United Kingdom; Jennifer Roberts, PhD, University of Sheffield, Sheffield, United Kingdom; Karl Taylor, PhD, University of Sheffield, Sheffield, United Kingdom

4:28 pm – 4:45 pm (108.2) Exploring the association between patient-reported outcomes and patient-generated health data from a wearable device in cancer patients.

Tempei Miyaji, MSc, Department of Clinical Trial Data Management, Graduate School of Medicine, The University of Tokyo, Bunkyo-ku, Japan; Takashi Kawaguchi, PhD, Department of Practical Pharmacy, School of Pharmacy, Tokyo University of Pharmacy and Life Sciences, Hachioji-city, Japan; Kanako Azuma, BSc., Department of Pharmacy, Tokyo Medical University Hospital, Shinjuku-ku, Japan; Shinya Suzuki, PhD., Department of Pharmacy, Kanagawa Prefectural Keiyukai Keiyu Hospital, Yokohama-shi, Japan; Yoko Sano, BSc., Department of Pharmacy, Tokyo Medical University Hospital, Shinjuku-ku, Japan; Moe Manabe, BSc., Department of Pharmacy, Tokyo Medical University Hospital, Shinjuku-ku, Japan; Ayako Torii, MSc., Department of Pharmacy, Tokyo Medical University Hospital, Shinjuku-ku, Japan; Tadamasu Kamimura, BSc., Department of Pharmacy, Kanagawa Prefectural Keiyukai Keiyu Hospital, Yokohama-shi, Japan; Yuki Ozawa, BSc., Department of Pharmacy, Kanagawa Prefectural Keiyukai Keiyu Hospital, Yokohama-shi, Japan; Takuhiro Yamaguchi, PhD., Division of Biostatistics, Tohoku University Graduate School of Medicine, Sendai, Japan

4:46 pm – 5:03 pm (108.3) Evaluation of the Implementation of PROMIS CAT Batteries for Total Joint Arthroplasty in an Electronic Health Record

Nan Rothrock, PhD, Northwestern University, Chicago, IL, United States; Cynthia Barnard, Northwestern Memorial HealthCare, Chicago, IL, United States; Surabhi Bhatt, Northwestern University, Chicago, IL, United States; Zeeshan Butt, Northwestern University, Chicago, IL, United States; Ryan Chmiel, Northwestern Memorial HealthCare, Chicago, IL, United States; Carl Christensen, Northwestern Memorial HealthCare, Chicago, IL, United States; Beghum Kutay, Northwestern Memorial HealthCare, Chicago IL, United States; David Manning, Northwestern University, Chicago, IL, United States; Nicole McGuire, Northwestern Memorial HealthCare, Chicago, IL, United States; Terrance Peabody, Northwestern University, Chicago, IL, United States; Luke Rasmussen, Northwestern University, Chicago, IL, United States; Michael Schachter, Northwestern Memorial HealthCare, Chicago, IL, United States; Justin Starren, Northwestern University, Chicago, IL, United States; Michael Stover, Northwestern University, Chicago, IL, United States; David Cella, Northwestern University, Chicago, IL, United States

5:04 pm – 5:21 pm (108.4) Feasibility of digital self-report PRO data for monitoring adverse events after discharge following major abdominal cancer surgery: the eRAPID study

Kerry Avery, University of Bristol, Bristol, United Kingdom; Hollie Richards, University of Bristol, Bristol, United Kingdom; Amanda Portal, University of Bristol, Bristol, United Kingdom; Trudy Reed, University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom; Ruth Harding, University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom; Robert Carter, University of Leeds, Leeds, United Kingdom; Kate Absalom, University of Leeds, Leeds, United Kingdom; Galina Velikova, Prof, University of Leeds, Leeds, United Kingdom; Jane Blazeby, Prof, University of Bristol, Bristol, United Kingdom

Scientific Program — Thursday, 25 October

5:30 pm - 6:30 pm JPRO Editorial Board Meeting (closed event) Meeting Room 7, Second Floor

5:50 pm - 6:20 pm Tricks of the Trade Presentation Pembroke & Herbert, Ground Floor

Making the connections that work: academic social networking

As new investigators, making the right connections through your academic network is critical for your career development. Come to join us at the Tricks of the Trade session to learn how to strategically build your network to advance your career goals and research program—all while balancing life roles such as raising a young family. The session starts with the speaker's individual presentation, and is followed by lively discussion between the speaker and the audience.

Speaker:

Skye Barbic, PhD, University of British Columbia, Vancouver, British Columbia, Canada

The Tricks of the Trade is intended for New Investigators but all conference attendees are welcome to attend and contribute to the discussion.

6:30 pm - 7:30 pm Mentor/Mentee Reception Munster & Leinster Suites, Ground Floor

Pre-registration is required for the mentor/mentee reception.

The ISOQOL mentoring program promotes career development and provides networking opportunities for students and new investigators within the society. Individuals interested in serving as a Mentor are paired with students and new investigators who are signed up for the program as Mentees. This reception provides a forum for the exchange of knowledge in a relaxed atmosphere. Refreshments are provided.



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Scientific Program — Friday, 26 October

7:00 am - 5:45 pm Registration Desk Open Pre-Function Area, Ground Floor

7:45 am - 8:45 am SIG Council Meeting (Closed Event) Meeting Room 1+2, Second Floor

7:45 am - 8:45 am Roundtables (Ticket Required) Second Floor

Roundtables are informal meetings with up to nine participants to network and discuss mutual interests on a particular topic. A ticket is required to participate in a roundtable discussion.

RT01: Interpretability of PROs in clinical practice Meeting Room 5
Host: Claire Snyder, PhD, Johns Hopkins University, Baltimore, MD, United States

RT02: Identifying responders to treatment Meeting Room 5
Host: Ron Hays, PhD, UCLA, Los Angeles, CA, United States

RT03: The EORTC QLQ-C30: Past, present and future. Meeting Room 6
Hosts: Neil Aaronson, PhD, The Netherlands Cancer Institute, Amsterdam, The Netherlands;
Kim Cocks, PhD, Adelphi Values, Cheshire, United Kingdom

RT04: Online monitoring of symptoms and side-effects during cancer treatment..... Meeting Room 6
Host: Galina Velikova, MD, PhD, FRCP, University of Leeds, Leeds, United Kingdom

RT05: Maximising the uptake and implementation of SPIRIT-PRO Guidance Meeting Room 6
Host: Melanie Calvert, PhD, The University of Birmingham, Birmingham, United Kingdom

RT06: Identifying dogmas in quality-of-life research: How to enrich our field Meeting Room 7
Host: Mirjam Sprangers, PhD, Academic Medical Center, Leiden, The Netherlands

RT07: PRO-PMs (PRO-based performance measures) Meeting Room 7
Host: Albert Wu, MD MPH, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States

RT08: Smashing the glass ceiling – Women in leadership Meeting Room 9
Host: Lotte Haverman, PhD, Emma Children's Hospital - Academic Medical Centre, Amsterdam, The Netherlands

RT09: Patient-centered research to support product development in the pharmaceutical industry . Meeting Room 9
Host: Josephine Norquist, MS, Merck Sharp & Dohme Corp, North Wales, PA, United States

RT10: PROs in clinical trials - what could possibly go wrong? Meeting Room 9
Host: Madeleine T. King, PhD, University of Sydney, Sydney, NSW, Australia

9:00 am - 10:30 am Plenary: Big data to support research and health care Pembroke & Herbert, Ground Floor

Sponsored by: EORTC



Digital data capture is now commonplace in everyday life – from public and patients recording health data using apps and digital tracking devices to consumer data generated from our online purchases. Key questions are whether and how these data can be brought together to improve health, and the implications of data sharing for personal privacy and citizenship. In this plenary, we explore the opportunities and challenges that working with big data brings.

Chair

Claire Snyder, PhD, Johns Hopkins University School of Medicine, Baltimore, MD, United States

Speakers

Emma Uprichard, University of Warwick, Coventry, United Kingdom

David Stillwell, PhD, Judge Business School, University of Cambridge, Cambridge, United Kingdom

Michael Schull, MD, MSc, FRCPC, Institute for Clinical Evaluative Sciences (ICES), Toronto, ON, Canada

Scientific Program — Friday, 26 October

10:30 am - 11:15 am Exhibits Open and Refreshment Break Fitzwilliam Suites, Ground Floor

10:35 am - 11:10 am Friday Poster Session I Lansdowne Room, Ground Floor

(2003) Measurement Invariance between Black and White Dialysis Patients and Normative Scores for the General Dialysis Population in the United States on The Kidney Disease Quality of Life 36-item Short-form Survey (KDQOL-36)

John Peipert, PhD, Northwestern University, Chicago, IL, United States; Kristi Klicko, BS, Medical Education Institute, Madison, WI, United States; Peter Bentler, PhD, UCLA, Los Angeles, CA, United States; Ron Hays, PhD, UCLA, Los Angeles, CA, United States

NEW INVESTIGATOR POSTER AWARD FINALIST

(2005) Psychometric Properties in the Face of Missing Data - A Simulation Study Assessing the Effect of Missing Data on Test-Retest Reliability in Diary Studies

Philip Griffiths, PhD, Clinical Outcomes Solutions, Folkestone, United Kingdom; Lysbeth Floden, MPH, Clinical Outcomes Solutions, Tucson, AZ, United States; Helen Doll, Clinical Outcomes Solutions, Folkestone, United Kingdom; Mark Morris, MSc, Clinical Outcomes Solutions, Folkestone, United Kingdom; Stacie Hudgens, MA (AbD), Clinical Outcomes Solutions, Tucson, AZ, United States

NEW INVESTIGATOR POSTER AWARD FINALIST

(2007) Effects of Parental Psychopathology on Reports of Child Health-related Quality of Life

Irina Oltean, University of Waterloo, Waterloo, Ontario, Canada; **Mark Ferro, PhD, University of Waterloo, Waterloo, Ontario, Canada**

NEW INVESTIGATOR POSTER AWARD FINALIST

Breast Cancer

(2009) Examination of high symptom and functional burden in a US population-based breast cancer cohort using PROMIS

Ashley Smith, PhD, MPH, National Cancer Institute, Bethesda, MD, United States; Alexandra Greenberg-Worisek, PhD, Mayo Clinic College of Medicine, Rochester, MN, United States; Erin Kent, PhD, National Cancer Institute, Bethesda, MD, United States; Grace Zhou, MS, Lombardi Comprehensive Cancer Center, Bethesda, DC, United States; Sandra Mitchell, PhD, CRNP, National Cancer Institute, Bethesda, MD, United States; Theresa Keegan, PhD, MPH, UC Davis Comprehensive Cancer Center, Sacramento, CA, United States; Arnold Potosky, PhD, Lombardi Comprehensive Cancer Center, Washington, DC, United States; Roxanne Jensen, PhD, National Cancer Institute, Bethesda, MD, United States

(2011) Country-specific differences on patient reported outcomes for ability to work and pursue leisure activities in breast cancer clinical trial patients.

Bellinda King-Kallimanis, US Food and Drug Administration, Silver Spring, MD, United States; Lynn Howie, MD, US FDA, Silver Spring, MD, United States; Jennifer Gao, MD, US FDA, Silver Spring, MD, United States; Julia Beaver, MD, US FDA, Silver Spring, MD, United States; Paul Kluetz, MD, US FDA, Silver Spring, MD, United States

(2013) Quality of life at 2-year follow-up of SUPREMO randomized trial of post mastectomy radiotherapy for breast cancer

Galina Velikova, MD PhD, University of Leeds, Leeds, United Kingdom; Linda Williams, PhD, University of Edinburgh, Edinburgh, United Kingdom; Sarah Willis, MSc, London School of Hygiene and Tropical Medicine, London, United Kingdom; J. Michael Dixon, MD, Edinburgh Breast Unit, Western General Hospital, Edinburgh, United Kingdom; Juliette Lancaster, FRCR, The Christie Hospital, Manchester, Manchester, United Kingdom; Matthew Hatton, FRCR, Department of Clinical Oncology, Weston Park Hospital, Sheffield, Sheffield, United Kingdom; Jacqueline Clarke, FRCR, Cancer Centre, Belfast City Hospital, Belfast, United Kingdom; Ian H. Kunkler, FRCR, Edinburgh Cancer Research Centre, University of Edinburgh, Edinburgh, United Kingdom; Nicola S. Russell, PhD, The Netherlands Cancer Institute, Amsterdam, Amsterdam, Netherlands

(2015) Low Toxicity with Proton Beam Therapy for Isolated Locoregional Recurrence of Breast Cancer after Mastectomy without Prior Radiotherapy: Prospective PCG Registry Analysis

Joshua Niska, Mayo Clinic, Phoenix, AZ, United States; Cameron Thorpe, Mayo Clinic, Phoenix, AZ, United States; Marlene Girardo, Mayo Clinic, Phoenix, AZ, United States; Heidi Kosiorek, Mayo Clinic, Phoenix, AZ, United States; Lisa McGee, Mayo Clinic, Phoenix, AZ, United States; William Hartsell, Proton Collaborative Group, Warrenville, IL, United States; Gary Larson, ProCure Proton Therapy Center, Oklahoma City, OK, United States; Carl Rossi, Scripps, San Diego, CA, United States; Henry Tsai, ProCure Proton Therapy Center, Somerset, NJ, United States; Carlos Vargas, Mayo Clinic, Phoenix, AZ, United States

(2017) Quality of Life study in elderly breast cancer survivors. Differences among axillary surgery groups

Juan Ignacio Arraras, Complejo Hospitalario de Navarra, Pamplona, Spain; Ana Manterola, Oncologist, Complejo Hospitalario de Navarra, Pamplona, Spain; Jose Juan Illarramendi, Complejo Hospitalario de Navarra, Pamplona, Spain; Gemma Asin, Complejo Hospitalario de Navarra, Pamplona, Spain; Esteban Salgado, Complejo Hospitalario de Navarra, Pamplona, Spain; Berta Ibañez, Navarrabiomed- Departamento de Salud-UPNA - REDISSEC, Methodology Unit, Pamplona, Spain; Miguel Angel Dominguez, Complejo Hospitalario de Navarra, Pamplona, Spain; Uxue Zarandona, Complejo Hospitalario de Navarra, Pamplona, Spain; Susana de la Cruz, Complejo Hospitalario de Navarra, Pamplona, Spain; Ruth Vera, Complejo Hospitalario de Navarra, Pamplona, Spain

HELPING TO SHAPE THE FUTURE

Congratulations to the three Evidera research scientists selected to chair ISOQOL Special Interest Groups (SIGs).



Carla Dias-Barbosa, MSc
Chair Elect
Mixed Methods



Huda Shalhoub, PhD
Chair Elect
Translation & Cultural Adaptation



Hilary Wilson, PhD
Chair
Patient Engagement

Scientific Presentations During ISOQOL 2018

WORKSHOPS

Concept Elicitation for the Development of Clinical Outcome Assessments (COAs) - Qualitative Approaches for Data Collection, Analyses and Reporting

Evidera speakers: Hareendran A, Skalicky A

Clinical Outcome Assessment in a Multi-Cultural Context: Measurement Challenges and Solutions

Evidera speaker: Martin M

POSTERS

Development of a Patient Reported Measure of Quality of Care Transitions: Evidence of Structural Validity

Evidera authors: Anatchkova M, Atkinson M

The American Neurogastroenterology and Motility Society Gastroparesis Cardinal Symptom Index-Daily Diary (ANMS GCSI-DD): Assessing Qualitative Validity and Electronic Usability in Patients with Idiopathic or Diabetic Gastroparesis

Evidera authors: Revicki DA, Gleeson S, Speck R

(2019) Health-related quality of life outcomes for The LEAP Study - CALGB 70305 (Alliance): a lymphedema prevention intervention trial for newly diagnosed breast cancer patients

Michelle Naughton, Ph.D., M.P.H., The Ohio State University Comprehensive Cancer Center, Columbus, OH, United States; Drew Seisler, M.S., Mayo Clinic, Rochester, MN, United States; Jeff Sloan, Ph.D., Mayo Clinic, Rochester, MN, United States; Heshan Liu, M.S., Mayo Clinic, Rochester, MN, United States; Jennifer Le-Rademacher, Ph.D., Mayo Clinic, Rochester, MN, United States; Jill Oliveri, D.PH, The Ohio State University Comprehensive Cancer Center, Columbus, OH, United States; Armer Jane, Ph.D., University of Missouri, Columbia, MO, United States; Gary Unzeitig, M.D., Doctor's Hospital of Laredo, Laredo, TX, United States; Michael Schwartz, M.D., Mount Sinai Medical Center, Miami Beach, FL, United States; Marianne Melnik, M.D., Cancer Research Consortium of West Michigan, Grand Rapids, MI, United States; John Taylor, M.A., University of Chicago, Chicago, IL, United States; Electra Paskett, Ph.D., The Ohio State University Comprehensive Cancer Center, Columbus, OH, United States

(2021) Health-Related Quality of Life Among Breast Cancer Survivors and Non-Cancer Controls: Pink SWAN

Nancy Avis, PhD, Wake Forest School of Medicine, Winston-Salem, NC, United States; Beverly Levine, PhD, Wake Forest School of Medicine, Winston-Salem, NC, United States; Alicia Colvin, PhD, University of Pittsburgh Department of Epidemiology, Pittsburgh, PA, United States; Joyce Bromberger, PhD, University of Pittsburgh Department of Psychiatry, Pittsburgh, PA, United States; Rachel Hess, MD, School of Medicine, University of Utah, Salt Lake City, UT, United States; Gail Greendale, MD, David Geffen School of Medicine at UCLA, Los Angeles, CA, United States

(2023) Efficacy of Internet-based cognitive behavioral therapy for treatment-induced menopausal symptoms in breast cancer survivors: results of a randomized controlled trial

Vera Atema, Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Marieke van Leeuwen, PhD., Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Jacobien M. Kieffer, PhD., Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Hester S.A. Oldenburg, MD; PhD., Department of Surgical Oncology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Marc van Beurden, MD; PhD., Department of Gynecology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Myra S. Hunter, PhD., Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, Kings College London, London, United Kingdom; **Neil K. Aaronson, PhD., Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands**

CAT and Item Banks

(2025) Organizing the EORTC Item Library: A Mixed Methods: Exploratory Content Analysis

Claire Piccinin, EORTC, Brussels, Belgium; Dagmara Kulis, EORTC, Brussels, Belgium; Andrew Bottomley, EORTC, Brussels, Belgium; Francesca Martinelli, EORTC, Brussels, Belgium; Justyna Mierzynska, EORTC, Brussels, Belgium; Madeline Pe, EORTC, Brussels, Belgium; Mogens Groenvold, University of Copenhagen, Copenhagen, Denmark

(2027) Streamlining assessment of patient satisfaction with body appearance by applying multidimensional computerized adaptive testing to the BODY-Q.

Daan Geerards, M.D., Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States; Anne Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada; Maarten Hoogbergen, MD, PhD, Catharina Ziekenhuis, Eindhoven, Netherlands; Andrea Pusic, MD, MSc, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States; **Christopher Gibbons, PhD, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States**

(2029) Translations of item lists created with the EORTC Item Library: updated translation and review procedure

Dagmara Kulis, MA, EORTC, Brussels, Belgium; Claire Piccinin, EORTC, Brussels, Belgium; Andrew Bottomley, PhD, EORTC, Brussels, Belgium; Mogens Groenvold, PhD, University of Copenhagen, Copenhagen, Denmark

(2031) Relative validity of an emotional functioning short form based on the EORTC CAT item bank, an international study with >1,000 patients with advanced cancer

Ida Korfage, Erasmus MC, Rotterdam, Netherlands; Lea Jasmina Jabbarian, Erasmus MC, Rotterdam, Netherlands; Morten Petersen, Bispebjerg Hospital, Copenhagen, Denmark; Caroline Arnfeldt Christensen, University of Copenhagen, Copenhagen, Denmark; Luc Deliens, Vrije Universiteit Brussel, Brussels, Belgium; Agnes van der Heide, Erasmus MC, Rotterdam, Netherlands; Marijke Kars, University Medical Center, Utrecht, Netherlands; Guido Miccinesi, Cancer Prevention and Research Institute (ISPO), Florence, Italy; Sheila Payne, Lancaster University, Lancaster, United Kingdom; Andrew Wilcock, University of Nottingham, Nottingham, United Kingdom; Mogens Groenvold, Bispebjerg Hospital, Copenhagen, Denmark

(2033) International validation of the EORTC QLQ-CAT

Morten Aa. Petersen, The Research Unit, Department of Palliative Medicine, Bispebjerg og Frederiksberg Hospital, Copenhagen NV, Denmark; Neil K. Aaronson, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Thierry Conroy, Medical Oncology Department, Institut de cancérologie de Lorraine, Vandoeuvre-lès-Nancy, France; Anna Costantini, Psychoncology Unit, Sant'Andrea Hospital, Faculty of Medicine and Psychology Sapienza University, Rome, Italy; Eva Hammerlid, Dept of Otolaryngology Head and Neck Surgery, Sahlgrenska University Hospital, Göteborg University, Göteborg, Sweden; Bernhard Holzner, Department of Psychiatry and Psychotherapy, Innsbruck Medical University, Innsbruck, Austria; Colin Johnson, Surgical Unit, Faculty of Medicine, University of Southampton, Southampton, United Kingdom; Jacobien M. Kieffer, Division of Psychosocial Research and Epidemiology, the Netherlands Cancer Institute, Amsterdam, Netherlands; Marieke van Leeuwen, Division of Psychosocial Research and Epidemiology, the Netherlands Cancer Institute, Amsterdam, Netherlands; Sandra Nolte, Department of Psychosomatic Medicine, Center for Internal Medicine and Dermatology, Charité - Universitätsmedizin Berlin, Berlin, Germany; Krzysztof A. Tomaszewski, Health Outcomes Research Unit, Department of Gerontology, Geriatrics, and Social Work, Faculty of Education, Ignatianum Academy, Krakow, Poland; Annika Waldmann, Institute for Social Medicine and Epidemiology, University Luebeck, Luebeck, Germany; Teresa Young, East & North Hertfordshire NHS Trust incorporating Mount Vernon Cancer Centre, Northwood, United Kingdom; Paola Zotti, Scientific Directorate CRO Aviano National Cancer Institute -IRCCS, Aviano, Italy; Mogens Groenvold, The Research Unit, Department of Palliative Medicine, Bispebjerg og Frederiksberg Hospital, Copenhagen, Denmark

Chinese Medicine

(2035) *Withdrawn*

(2037) Fatigue reduction by Renshen Yangrong Tang (RSYRT) in patients with cancer: A randomized, double blind, active agent controlled clinical trial

Xin Shelley Wang, MD, MPH, MD Anderson Cancer Center, Houston, TX, United States; Qiuling Shi, MD, PhD, MD Anderson Cancer Center, Houston, TX, United States; Yichen Xu, MD, Peking University Cancer Hospital, Beijing, China; Tsun Hsuan Chen, BS, MD Anderson Cancer Center, Houston, TX, United States; Pingping Li, MD, Peking University Cancer Hospital, Beijing, China

(2039) Quantitative Analysis of Syndrome Differentiation in Chinese Medicine for Chronic Superficial Gastritis with Structural Equation Modeling

Zhongyu Huang, Guangzhou University of Chinese Medicine, Canton, China; Fengbin Liu, MD, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China; Zhengkun Hou, MD, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China; Xianhua Liu, MD, Shenzhen Baoan Traditional Chinese Medicine hospital group, Shenzhen, China; **Zhuoqun Chen, Master, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China**

Lung Cancer

(2041) Health-related quality of life in patients investigated for suspected lung cancer

Lars E. Eriksson, Karolinska Institutet and City, University of London, Stockholm, Sweden; Sara Runesdotter, Statistician, Karolinska Institutet, Stockholm, Sweden; Adrian Levitsky, PhD, Karolinska Institutet, Stockholm, Sweden; Britt-Marie Bernhardson, RN, PhD, Karolinska Institutet, Stockholm, Sweden

(2043) Patient reported outcomes from patients with lung cancer treated with curatively intended surgery

Majken Broenserud, Odense Patient data Exploratory Network (OPEN), Odense University Hospital/Institute of Clinical Research, University of Southern Denmark, Odense, Denmark; Maria Iachina, Center for Clinical Epidemiology and Research Unit of Clinical Epidemiology, Odense University Hospital, Odense, Denmark; Anders Green, Odense Patient data Exploratory Network (OPEN), Odense University Hospital/Institute of Clinical Research, University of Southern Denmark, Odense, Denmark; Mogens Grønqvold, Research Unit, Department of Palliative Medicine, Bispebjerg Hospital, and Department of Public Health, University of Copenhagen, Odense, Denmark; Erik Jakobsen, Odense Patient data Exploratory Network (OPEN), Odense University Hospital/Institute of Clinical Research, University of Southern Denmark, and The Danish Lung Cancer Registry, Department of Thoracic Surgery, Odense University Hospital, Odense, Denmark

(2045) Patient Reported Outcomes used for Weekly Internet-based DEtection of progressive disease in lung cancer; PRO-WIDE a national multicenter randomized controlled trial – a study design

Rasmus Blechingberg Friis, Department of Oncology, Regional Hospital West Jutland, Herning, Denmark; Niels Henrik Hjøllund, MD, Professor, AmbuFlex/WestChronic, Occupational Medicine, Herning and Department of Epidemiology, Aarhus University Hospital, Denmark, Herning, Denmark; Caroline Mejdahl, Cand.scient.san, PhD student, AmbuFlex/WestChronic, Occupational Medicine, Herning, Herning, Denmark; Halla Skuladottir, MD, PhD, Department of Oncology, Regional Hospital West Jutland, Herning, Denmark

Meaning in Measurement

(2047) *Withdrawn*

(2049) Impact of Completing Pediatric Patient-Reported Outcome Measures that ask about Appearance of Cleft Lip and/or Palate

Anne Klassen, McMaster University, Hamilton, Ontario, Canada; Elena Tsangaris, Harvard University, Boston, MA, United States; Tim Goodacre, Oxford University, Oxford, United Kingdom; Christopher Forrest, Hospital for Sick Children, Toronto, Ontario, Canada; Karen Wong Riff, Hospital for Sick Children, Toronto, Ontario, Canada

(2051) Comparing individualized measures of quality of life with standard outcome measures in people with Parkinson's Disease

Ayse Kuspinar, BSc(PT), MSc, PhD, McMaster University, Hamilton, Ontario, Canada; Kedar Mate, MSc, PhD(c), McGill University, Montreal, Quebec, Canada; Nancy Mayo, BSc(PT), MSc, PhD, McGill University, Montreal, Quebec, Canada

(2053) Understanding “Recovery” Following Ankle Reconstruction: a Qualitative Study

Ellie Pinsker, BA&Sc, PhD cand., St. Michael's Hospital, Toronto, Ontario, Canada; Monique Gignac, PhD, Institute of Work and Health, Toronto, Ontario, Canada; Joanna Sale, PhD, St. Michael's Hospital, Toronto, Ontario, Canada; Timothy Daniels, MD, FRCSC, St. Michael's Hospital, Toronto, Ontario, Canada; **Dorcas Beaton, PhD, Institute of Work and Health, Toronto, Ontario, Canada**

(2055) Investigation of two commonly used response expectancies scales: Are they capturing the same construct?

Elise Devlin, School of Psychology, The University of Adelaide, Adelaide, Australia; **Hayley Whitford, PhD, University of South Australia Cancer Research Institute, Adelaide, Australia;** Linley Denson, MPsych(Clin), PhD, School of Psychology, The University of Adelaide, Adelaide, Australia

(2057) Hermeneutics as a 'lens' in the interpretation of patient-reported outcome measures

Jae-Yung Kwon, University of British Columbia, Vancouver, British Columbia, Canada; Sally Thorne, University of British Columbia, Vancouver, British Columbia, Canada; Richard Sawatzky, Trinity Western University, Langley, British Columbia, Canada

(2059) Recall bias in the retrospective measurement of health-related quality of life

Janine Topp, University Medical Center Hamburg, Hamburg, Germany; Valerie Andrees, University Medical Center Hamburg, Hamburg, Germany; Matthias Augustin, University Medical Center Hamburg, Hamburg, Germany; Laura Schaefer, University Medical Center Hamburg, Hamburg, Germany; Christoph Heesen, University Medical Center Hamburg, Hamburg, Germany; Christine Blome, University Medical Center Hamburg, Hamburg, Germany

(2061) Further structural validation of the Long-Term Conditions Questionnaire (LTCQ): Formation of the Rasch 8-item LTCQ short-form (LTCQ-8)

Laurie Batchelder, PSSRU, University of Kent, Canterbury, United Kingdom; Diane Fox, PSSRU, University of Kent, Canterbury, United Kingdom; **Caroline Potter, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom;** Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Julien Forder, PSSRU, University of Kent, Canterbury, United Kingdom; Karen Jones, PSSRU, University of Kent, Canterbury, United Kingdom; Michele Peters, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

(2063) Shifting the validation paradigm for patient-reported outcome measures (PROMs): assembling and evaluating quantitative and qualitative validity evidence

Melanie Hawkins, Deakin University, Melbourne, Victoria, Australia; Sandra Nolte, PhD, Charité - Universitätsmedizin, Berlin, Germany; Gerald Elsworth, PhD, Deakin University, Melbourne, Australia; Richard Osborne, PhD, Deakin University, Melbourne, Australia

(2065) iPROMS: Different Questions, Different Answers

Nancy Mayo, BSc(PT), MSc, PhD, McGill University, Montreal, Quebec, Canada; Kedar Mate, BPT, MSc, McGill University, Montreal, Quebec, Canada; Xiao Ow, BSc(PT), MSc, McGill University, Montreal, Quebec, Canada; Mehmet Inceer, BPT, MSc, McGill University, Montreal, Quebec, Canada; Ana Maria Moga, BEng, BPT, MSc, McGill University, Montreal, Quebec, Canada; Navaldeep Kaur, BSc(PT), MSc, McGill University, Montreal, Quebec, Canada

(2067) Using Cognitive and Three-Step Test Interviews to pre-test the Warwick Axial Spondyloarthritis Tiredness and Energy (WASTEd) questionnaire: a co-constructed self-report questionnaire

Nathan Pearson, MSc, BSc (Hons), University of Warwick, Coventry, United Kingdom; Elizabeth Tutton, Warwick Research in Nursing, Warwick Medical School, University of Warwick, Coventry, United Kingdom; Jonathan Packham, Haywood Academic Rheumatology Centre, Staffordshire and Stoke-on-Trent Partnership NHS Trust, Stoke-on-Trent, United Kingdom; Helen Parsons, Clinical Trials Unit, Warwick Medical School, University of Warwick, Coventry, United Kingdom; Jane Martindale, Wrightington, Wigan and Leigh NHS Foundation Trust, Wigan, Manchester, United Kingdom; George Strickland, Wrightington, Wigan and Leigh NHS Foundation Trust, Wigan, Manchester, United Kingdom; Jean Thompson, Wrightington, Wigan and Leigh NHS Foundation Trust, Wigan, Manchester, United Kingdom; Kirstie Haywood, Warwick Research in Nursing, Warwick Medical School, University of Warwick, Coventry, United Kingdom

(2069) What is the meaning of quality of life for children with physical disabilities? A meta-synthesis of qualitative data

Nikki Ow, BOT, MA, McGill University, Montreal, Quebec, Canada; Adriana Appau, McGill University, Montreal, Quebec, Canada; Nancy Mayo, PhD, McGill University, Montreal, Quebec, Canada

(2071) Adaptation/Content Validation of Measure Yourself Medical Outcomes Profile (MYMOP) Questionnaire for 7-11 year old Children

Sana Ishaque, PhD (candidate), The University of Adelaide, Adelaide, Australia; Rachel Roberts, The University of Adelaide, Adelaide, Australia; Jonathan Karnon, The University of Adelaide, Adelaide, Australia; David Thomas, Women's and Children's Hospital, Adelaide, Australia; Amy Salter, The University of Adelaide, Adelaide, Australia

(2073) Exploring the Hidden Dynamics in Health-related Quality of Life

Tom Orel, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Denny Borsboom, Department of Psychology, University of Amsterdam, Amsterdam, Netherlands; Sacha Epskamp, Department of Psychology, University of Amsterdam, Amsterdam, Netherlands; Iris Hartog, Department of Medical Psychology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Pythia Nieuwkerk, Department of Medical Psychology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Jose Henriques, Department of Cardiology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Michael Scherer-Rath, Department Empirical and Practical Religious Studies, Radboud University Nijmegen, Nijmegen, Netherlands; Hanneke van Laarhoven, Department of Oncology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Justine Netjes, Department of Medical Psychology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands; Mirjam Sprangers, Department of Medical Psychology, Academic Medical Center (AMC) Amsterdam, Amsterdam, Netherlands

(2075) Differences between Patient- and Proxy-reported HRQoL Using the Wound-QoL

Rachel Sommer, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Carsten Hampel-Kalthoff, OrgaMed Healthcare Dortmund, Dortmund, Germany; Brigitte Kalthoff, OrgaMed Healthcare Dortmund, Dortmund, Germany; Christopher Neht, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Erwin Scherfer, OrgaMed Healthcare, Dortmund, Germany; Manfred Winkler, wundberatung-suedtndern, Südtondern, Germany; Christine Blome, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

Other Cancer

(2077) Development and Psychometric Evaluation of the Cancer Distress Scales for Adolescent and Young Adults (CDS-AYA)

Elena Tsangaris, Harvard University, Boston, MA, United States; Norma D'Agostino, Princess Margaret Cancer Centre, Toronto, Ontario, Canada; Charlene Rae, McMaster University, Hamilton, Ontario, Canada; Vicky Breakey, McMaster University, Hamilton, Ontario, Canada; Anne Klassen, McMaster University, Hamilton, Ontario, Canada

(2079) Fear of recurrence and view of life affect health-related quality of life in patients with differentiated thyroid carcinoma: a prospective Swedish population-based study

Christel Hedman, Karolinska Institutet, Department of Molecular Medicine and Surgery, Stockholm, Sweden; Therese Djärv, MD PhD, Karolinska Institutet, Department of Medicine, Solna, Stockholm, Sweden; Peter Strang, Professor, Karolinska Institutet, Department of Oncology-Pathology, Stockholm, Sweden; Catharina Ihre Lundgren, M.D., Ph.D, Karolinska Institutet, Department of Molecular Medicine and Surgery, Stockholm, Sweden

(2081) Risk Factors for Poor Quality of Life in Cancer Survivors with Multiple Chronic Conditions: Exploring the Role of Treatment Burden as a Mediator

David Eton, PhD, Mayo Clinic, Rochester, MN, United States; Roger T. Anderson, PhD, University of Virginia School of Medicine, Charlottesville, VA, United States; Wendy F. Cohn, PhD, University of Virginia School of Medicine, Charlottesville, VA, United States; Erin M. Kennedy, MPH, University of Virginia School of Medicine, Charlottesville, VA, United States; Kathryn J. Ruddy, MD, MPH, Mayo Clinic, Rochester, MN, United States

(2083) Effects of patient comorbidity and self-care burden on health-related quality of life in survivors of women's cancers.

Roger Anderson, PhD, University of Virginia, Charlottesville, VA, United States; Fabian Camacho, MS, University of Virginia, Charlottesville, VA, United States; Christiana Brenin, MD, University of Virginia, Charlottesville, VA, United States; Kimberly Carter, PhD, Carilion Clinic, Roanoke, VA, United States; David Eton, PhD, Mayo Clinic, Rochester, MN, United States; Philip Chow, PhD, University of Virginia, Charlottesville, VA, United States; Pamela DeGuzman, PhD, University of Virginia, Charlottesville, VA, United States; Thomas Guterbock, PhD, University of Virginia, Charlottesville, VA, United States; Erin Kennedy, MPH, University of Virginia, Charlottesville, VA, United States; Kathryn J. Ruddy, PhD, MPH, Mayo Clinic, Rochester, MN, United States; Wendy Cohn, PhD, University of Virginia, Charlottesville, VA, United States

(2085) Quality of life in patients with non-melanoma skin cancer and actinic keratosis: analysing effects of diagnoses and disease severity in a large patient cohort

Michael Koller, University Hospital, Regensburg, Germany; Karolina Müller, University Hospital, Regensburg, Germany; Wolfgang Philipp-Dormston, Cologne Dermatology, Cologne, Germany; Klaus Strömer, Professional Association of German Dermatologists, Moenchengladbach, Germany; Christian Termeer, Dermatology Practice, Stuttgart, Germany; Urte Hammann, Dermatology Practice, Stade, Germany; Johannes W. Glutsch, Dermatology Practice, Karlsruhe, Germany; Gertraud Krähn-Senftleben, Dermatology Practice, Blaubeuren, Germany; Hermann Lübbert, Biofrontera, Leverkusen, Germany; Ben Novak, Biofrontera, Leverkusen, Germany; Rolf-Markus Szeimies, Vest Clinic, Recklinghausen, Germany

(2087) Systematic review of patient-reported outcome measures used in randomised clinical trials testing checkpoint inhibitor immunotherapy for cancer

Michele Peters, University of Oxford, Oxford, United Kingdom; Rebecca Wiltshire, University of Oxford, Oxford, United Kingdom; Verna Lavender, Brookes University, Oxford, United Kingdom; Mark Middleton, University of Oxford, Oxford, United Kingdom; Michele Peters, University of Oxford, Oxford, United Kingdom

(2089) Follow-Up Assessment of Quality of Life in Patients With Recurrent Glioblastoma Undergoing Investigational Immune Therapy

Jennifer De Cremer, Vrije Universiteit Brussel, Brussels, Belgium; Anne Rogiers, Centre Hospitalier Universitaire Brugmann, Brussels, Belgium; Laila Ben Salama, Universitair Ziekenhuis Brussel, Brussels, Belgium; Jean Bernheim, Universitair Ziekenhuis Brussel, Brussels, Belgium; Bart Neyns, Universitair Ziekenhuis Brussel, Brussels, Belgium; Peter Theuns, Vrije Universiteit Brussel, Brussels, Belgium

(2091) Longitudinal study of behavioral and psychological changes following cancer – Measurement and changes in Post-Traumatic Growth over time

Solenne Martin, INSERM U1246 SPHERE - University of Nantes, Nantes, France; Myriam Blanchin, INSERM U1246 SPHERE - University of Nantes, Nantes, France; Marianne Bourdon, INSERM U1246 SPHERE - University of Nantes, Nantes, France; Angélique Bonnaud Aignac, INSERM U1246 SPHERE - University of Nantes, Nantes, France; **Véronique Sébille, INSERM U1246 SPHERE - University of Nantes, Nantes, France**

(2093) Outcome Measures Reported in Clinical Trials Evaluating the Management of Lymph Node Involvement in Melanoma: A Systematic Review.

Waqas Patel, Imperial College London, London, United Kingdom; Luke Geoghegan, BSc (Hons), Imperial College London, London, United Kingdom; Jeremy Rodrigues, MBChB (Hons) BSc (Hons) MSc PhD MRCS FRCS, University of Oxford, Oxford, United Kingdom; Abhilash Jain, MBBS MSc PhD MRCS FRCS (Plast), Imperial College London, London, United Kingdom; Rubeta N Matin, MBBS BSc(Hons) PhD MRCP FRCP (Derm), University of Oxford, Oxford, United Kingdom

PROMIS

(2095) Parent and Child Agreement on Itch Severity

Aaron Kaat, Northwestern University, Chicago, IL, United States; Amy S Paller, MD, Northwestern University, Chicago, IL, United States; Jin-Shei Lai, PhD, Northwestern University, Chicago, IL, United States

(2097) Patient- versus proxy-response on global health scales: no meaningful Difference

Brittany Lapin, PhD MPH, Cleveland Clinic, Cleveland, OH, United States; Nicolas Thompson, MS, Cleveland Clinic, Cleveland, OH, United States; Irene Katzan, MD, Cleveland Clinic, Cleveland, OH, United States

(2099) Qualitative development of the PROMIS Itch Questionnaire – Child (PIQ-C)

Cindy Nowinski, MD, PhD, Northwestern University, Chicago, IL, United States; Jin-Shei Lai, PhD, OTR, Northwestern University, Chicago, IL, United States; Amy Paller, MD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Sara Shaunfield, PhD, Northwestern University, Chicago, IL, United States; Jonathan Silverberg, MD, PhD, MPH, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; David Cella, PhD, Northwestern University, Chicago, IL, United States

(2101) Linking FACIT Fatigue data to PROMIS® Fatigue scores to enhance interpretability: Data from phase 3 baricitinib rheumatoid arthritis trials

Clifton O. Bingham III, Johns Hopkins Division of Rheumatology, Baltimore, MD, United States; David Cella, Department of Medical Social Sciences, Feinberg School of Medicine, Northwestern University, Chicago, IL, United States; Susan J. Bartlett, Departments of Clinical Epidemiology and Rheumatology, McGill University, Montreal, Quebec, Canada; Amy Delozier, Eli Lilly and Company, Indianapolis, IN, United States; Amanda Quebe, Eli Lilly and Company, Indianapolis, IN, United States; Luna Sun, Eli Lilly and Company, Indianapolis, IN, United States; Susan Ottawa, Eli Lilly and Company, Indianapolis, IN, United States; Carol L. Gaich, Eli Lilly and Company, Indianapolis, IN, United States

(2103) Identifying clinically meaningful severity categories for symptom experience or functional impairment for PROMIS Pediatric measures of anxiety, mobility, and fatigue in Juvenile Idiopathic Arthritis

Courtney M. Mann, MA, Duke University, Durham, NC, United States; Laura E. Schanberg, MD, Duke Medical Center, Durham, NC, United States; Mian Wang, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Emily von Scheven, MD, University of California at San Francisco, San Francisco, CA, United States; Nicole Lucas, Duke University, Duke, NC, United States; Bryce B. Reeve, PhD, Duke University, Durham, NC, United States

(2105) Psychometric Properties of the PROMIS® Itch Questionnaire – Child (PIQ-C)

Jin-Shei Lai, Northwestern University, Chicago, IL, United States; Amy S Paller, Northwestern University, Chicago, IL, United States; David Cella, Northwestern University, Chicago, IL, United States; Cindy Nowinski, Northwestern University, Chicago, IL, United States

(2107) Initial validation of Swedish PROMIS®-25 in an orthopaedic population of children with acute severe knee injury.

John Chaplin, PhD, CPsych, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden; Constanze Wartenberg, PhD, Quality Registry Centre West Götaland, Gothenburg, Sweden; Christina Peterson, PhD, Jönköping University, Jönköping, Sweden; Aina Danialsson, PhD, Sahlgrenska Academy at University of Gothenburg, Gothenburg, Sweden

(2109) Change in PROMIS Physical Function Scores for Bariatric Surgery

Joshua Biber, MS, MBA, University of Utah Health, Salt Lake City, UT, United States; Howard Weeks, MD, University of Utah, Salt Lake City, UT, United States; Ji won Chang, MPH, MPA, University of Utah Health, Salt Lake City, UT, United States; Craig Gale, MS, University of Utah Health, Salt Lake City, UT, United States; Heidi Cozart, University of Utah, Salt Lake City, UT, United States; Ellen Morrow, MD, University of Utah, Salt Lake City, UT, United States; Rachel Hess, MD, MS, University of Utah, Salt Lake City, UT, United States

(2111) Use of the PROMIS new physical health domains and the asthma impact scale in children with an acute asthma exacerbation

Ashima Singh, Medical College of Wisconsin, Milwaukee, WI, United States; Mahua Dasgupta, MS, Medical College of Wisconsin, Milwaukee, WI, United States; Pippa Simpson, PhD, Medical College of Wisconsin, Milwaukee, WI, United States; **Julie Panepinto, MD, MSPH, Medical College of Wisconsin, Milwaukee, WI, United States**

(2113) PROMIS-Preference (PROPr) Utility Score Responsiveness in a Community-Based Sample of U.S. Cancer Patients

Roxanne Jensen, Leidos Biomedical Research Inc., Rockville, United States; Tania Lobo, M.S., Lombardi Comprehensive Cancer Center, Washington, DC, United States; Sandra Mitchell, PhD, Outcomes Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, United States; Ashley Smith, PhD MPH, Outcomes Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, United States; Erin Kent, PhD, Outcomes Research Branch, Division of Cancer Control and Population Sciences, National Cancer Institute, Rockville, MD, United States; Janel Hanmer, MD, PhD, Division of General Internal Medicine, University of Pittsburgh, Pittsburgh, PA, United States

Prostate and Bladder

(2115) PRO instruments used in studies of prostate cancer since 1960

Alexandra Furber, Crystallise, East Tilbury, United Kingdom; **Cassandra Springate, PhD, Crystallise, East Tilbury, United Kingdom**

(2117) Quality of life in bladder cancer patients receiving chemotherapy; a real life experience.

Gry Taarnhøj, MD, Ph.D-student, Department of Oncology, Rigshospitalet, Copenhagen, Denmark; Henriette Lindberg, MD, PhD, Department of Oncology, University of Copenhagen, Herlev Hospital, Herlev, Denmark; Christoffer Johansen, Professor, MD, DMSC, PhD, Department of Oncology, University of Copenhagen, Rigshospitalet, Copenhagen, Denmark; Helle Pappot, MD, DMSC, Department of Oncology, University of Copenhagen, Rigshospitalet, Copenhagen, Denmark

(2119) Recovery of Patient-Reported Function and Body Image among Bladder Cancer Patients Treated with Cystectomy and Urinary Diversion

Scott Gilbert, MD, Moffitt Cancer Center, Tampa, FL, United States; Richard Reich, PhD, Moffitt Cancer Center, Tampa, FL, United States; Carl Henriksen, MS, University of Florida, Gainesville, FL, United States; Wade Sexton, MD, Moffitt Cancer Center, Tampa, FL, United States; Michael Poch, MD, Moffitt Cancer Center, Tampa, FL, United States; Philippe Spiess, MD, Moffitt Cancer Center, Tampa, FL, United States; Paul Crispen, MD, University of Florida, Gainesville, FL, United States

(2121) Challenges of Measuring Patient-Reported Urinary Function in Cystectomy Patients

Thomas M. Atkinson, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Bernard H. Bochner, MD, Memorial Sloan Kettering Cancer Center, New York, NY, United States; Yuelin Li, Ph.D., Memorial Sloan Kettering Cancer Center, New York, NY, United States; Bruce D. Rapkin, Ph.D., Albert Einstein College of Medicine/Montefiore Medical Center, Bronx, NY, United States

Response Shift

(2123) Sharing complex statistical methods with diverse knowledge users: A knowledge translation study protocol

Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Ronak Brahmabhatt, MPH, Trinity Western University, Langely, British Columbia, Canada; Kathryn Sibley, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Tolulope Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Lisa Lix, PhD, University of Manitoba, Winnipeg, Manitoba, Canada; Anne Gadermann, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Lena Cuthbertson, BHScOT, Med, British Columbia Ministry of Health & Providence Health Care, Vancouver, British Columbia, Canada; Bruno Zumbo, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Richard Sawatzky, PhD, Trinity Western University & Centre for Health Evaluation and Outcome Sciences, Langley, British Columbia, Canada

(2125) Comparison of methods for response shift detection at item level: a simulation study

Myriam Blanchin, U1246 SPHERE - Université de Nantes, Nantes, France; Alice Guilleux, U1246 SPHERE - Université de Nantes, Nantes, France; Jean-Benoit Hardouin, U1246 SPHERE - Université de Nantes, Nantes, France; Véronique Sébille, U1246 SPHERE - Université de Nantes, Nantes, France

(2127) Using structural equation modeling to detect response shift and true change in common disability measures for patients undergoing spine surgery

Richard Skolasky, Johns Hopkins University, Baltimore, United States; Brian Neuman, M.D., Johns Hopkins University, Baltimore, MD, United States; Lee Riley, M.D., Johns Hopkins, Baltimore, MD, United States

Sexual Functioning

(2129) Psychometric Evaluation of PROMIS® Sexual Function and Satisfaction Measures in a Longitudinal Population-based Cohort of Men with Localized Prostate Cancer

Bryce Reeve, Duke University School of Medicine, Durham, NC, United States; Mian Wang, PhD, University of North Carolina, Chapel Hill, NC, United States; Kevin Weinfurt, PhD, Duke University School of Medicine, Durham, NC, United States; Kathryn Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States; Deborah Usinger, University of North Carolina, Chapel Hill, NC, United States; Ronald Chen, MD, University of North Carolina, Chapel Hill, NC, United States

(2131) Prevalence and predictors of erectile dysfunction in men with prostate cancer before and after hypofractionated radiotherapy.

Elke Rammant, Ghent University, Ghent, Belgium; Martijn Swimberghe, Ghent University Hospital, Ghent, Belgium; Piet Ost, Ghent University Hospital, Ghent, Belgium; Renée Bultijnck, Ghent University, Ghent, Belgium; Gert De Meerleer, UZ Leuven, Leuven, Belgium; Valérie Fonteyne, Ghent University Hospital, Ghent, Belgium

(2133) Sexual dysfunction and reproductive concerns in young women with breast cancer: Type, prevalence, and predictors of problems

Lisa Ljungman, Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden; Johan Ahlgren, Faculty of Medicine and Health, Örebro University, Örebro, Sweden; Lena-Marie Petersson, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Stockholm, Sweden; Kathryn Flynn, Department of Medicine, Medical College of Wisconsin, Milwaukee, WI, United States; Kevin Weinfurt, Department of Population Health Sciences, Duke University School of Medicine, Durham, NC, United States; Jessica Gorman, College of Public Health and Human Sciences, Oregon State University, Corvallis, OR, United States; Claudia Lampic, Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden; **Lena Wettergren, Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden**

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11:15 am - 12:30 pm Concurrent Symposium Sessions

Symposium 1: Minimising Research Waste and Maximising the Impact of Patient Reported Outcome Trial Results Pembroke & Herbert, Ground Floor

Moderator:

Melanie Calvert, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom

Discussants:

Madeleine King, BSc (Hons), DipMedStat, PhD, University of Sydney, Sydney, Australia

Michael Brundage, MD, MSc, Queen's Cancer Research Institute, Kingston, ON, Canada

Patient-reported outcome data from clinical trials can provide valuable evidence to inform shared decision-making, pharmaceutical labelling claims, clinical guidelines, and health policy. If collected, analysed, and reported appropriately, use of these data can promote patient centered-care. These data are particularly important to inform treatment decisions when similar survival benefits are observed but alternative treatments have differing side effects and impacts on quality of life.

Despite the potential benefits of PRO data, a number of challenges remain that may result in research waste, in terms of patient and researcher time and funders' money. "Approaches that can be used to maximise the impact of PRO trial results include (1) high-quality PRO protocol content; (2) minimising missing data; (3) standardising approaches for analysing and interpreting PRO endpoint to facilitate comparisons across clinical trials; (4) promotion of the ISOQOL and CONSORT-PRO guidelines for PRO trial data reporting; and (5) consistent graphical display of PRO results in the literature to aid interpretation and promote use in clinical practice."

This symposium will summarise and discuss the latest developments in the field which aim to improve the design, implementation, analysis, and reporting of PRO data to minimise waste and maximise patient benefit, and will explore how ISOQOL members can promote implementation and uptake.

Individual Presenters:

Improving the design and reporting of PRO trial data: implementation of the SPIRIT-PRO and CONSORT-PRO Extensions.

Melanie Calvert, PhD, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom

Missing patient-reported outcome data: understanding associated factors and strategies to reduce its instance and impact through careful design, quality assurance and reporting

Madeleine King, BSc (Hons), DipMedStat, PhD, University of Sydney, Sydney, Australia

Setting Standards for Analysis of Patient Reported Outcomes and Quality of Life Data for International Cancer Clinical Trials (SISAQOL consortium): Progress update

Andrew Bottomley, PhD, EORTC, Brussels, Belgium

Best practice recommendations for presenting PRO data in peer-reviewed journals

Claire Snyder, PhD, Johns Hopkins School of Medicine, Baltimore, MD, United States

Symposium 2: Clinical Outcomes Assessment Use in Rare Disease Studies: Real Life Examples from Clinicians, Patient Advocates, Industry, and Measurement Experts Meeting Room 1+2, Second Floor

Sponsored by: Pfizer



Moderator:

Michelle K. White, PhD, Optum, Johnston, RI, United States

Regulatory agencies have recognized the need for attention to COAs in rare disease studies, and in 2017, ISPOR published rare disease good practices guidelines. But what happens in real life when these strategies are implemented? How do clinicians and researchers deal with unexpected challenges and what new and innovative solutions are being applied to achieve the end goal of better understanding the burden that a patient faces with a rare disease? This symposium incorporates strategies for research in rare diseases and how those strategies work in real life from four perspectives: clinicians, patients/caregivers, industry, and measurement experts. The symposium presents examples of the use of generic patient reported outcome measures in describing HRQOL burden in patients with rare diseases as well as examples of the development and use of disease-specific measures. We will present examples of unique recruitment and patient engagement

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approaches in online observational studies of patients with rare diseases, and novel COA strategies that incorporate the use of technology to allow for more frequent, observed evaluation based on videotaped performance measures and accompanying observer reported outcome measures. We will also present the clinician perspective on using COAs in practice and research in patients with rare diseases.

Individual Presenters:

How we adapted standard disease-specific COA content validation approaches to better meet the challenges of rare disease: Three case studies

Michelle K. White, PhD, Optum, Johnston, RI, United States

Using technology to develop a novel physical function and quality of movement performance outcome assessment in patients with Duchenne's muscular dystrophy (DMD)

Mindy Leffler, MEd, Casimir, Plymouth, MA, United States

Overcoming research challenges in observational studies of rare diseases: Lessons learned from amyloid light chain amyloidosis

Tiffany Quock, PhD, MS, Prothena Biosciences Inc., South San Francisco, CA, United States

Patient-reported outcomes in clinical care and clinical trial settings: A clinician's experience in amyloid light chain (AL) amyloidosis

Anita D'Souza, MD, MS, Medical College of Wisconsin, Milwaukee, WI, United States

Symposium 3:

Challenges in itembanking - future perspectives on development and application

Meeting Room 9, Second Floor

Moderator:

Jan R. Boehnke, University of Dundee, Dundee, United Kingdom

In the past years, itembanking has helped in quality of life research to build shorter but still precise tests, and it offers a perspective to standardize measurement of Patient-Reported Outcomes (PROs) by overcoming the use of fixed instruments, which are not necessarily appropriate for every situation or population. This symposium convenes five teams from Europe and the USA working on the methodological development and clinical implementation of itembank methodology. The symposium will present and discuss recent approaches to tackle key challenges in development, maintenance, and application of itembanks in quality of life research.

The symposium will start off with a comparison of different techniques to build itembanks. Inspired by Cook and Campbell's (1979) approach for research design, a taxonomy of instrument development approaches is presented that shows that instrument development necessitates choices between multiple competing goals and can guide researchers to identify the optimal approach for their specific task at hand (Smits). The next two talks focus on embracing the multidimensional nature of health-related quality of life (as well as many other PROs) with multidimensional itembanks and CATs. Simulation studies based on existing itembanks and real patient data are used to explore whether results on efficiency gains through multidimensional itembanks known from educational research translate to health measurement (Paap). Another potential approach for multidimensional assessments are 'meta-banks' and the third talk presents research into how conceptual and empirical overlap needs to be assessed to combine different itembanks in such a 'meta-bank' (Kaat). Then, we will discuss the effects on data analysis when plausible value imputation is used to account for measurement error inherent in individual scores from itembanks. Ignoring such measurement error leads to an underestimation of variance and the size of such effects is explored in a recent European quality of life survey (Fischer). Finally, we will explore the potential to use patient feedback and patient generated content to refine itembanks and enhance the relevance of assessments of HRQOL (Gibbons).

At the end of the session, the audience will have the chance to discuss the presentations and their experiences in an open Q&A round.

Individual Presenters:

On the many trade-offs in item bank construction

Niels Smits, University of Amsterdam, Amsterdam, Netherlands

Imputation of plausible values to account for measurement error in analysis of quality of life data

Felix Fischer, Charite - Universitätsmedizin Berlin, Berlin, Germany

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Evaluating the incremental value of multidimensional computerized adaptive tests (MCATs) under different scenarios

Muirne Paap, PhD, University of Groningen, Groningen, Netherlands

Meta-Banks: Aggregating item banks for score comparability

Aaron Kaat, PhD, Northwestern University, Chicago, IL, United States

Future perspectives on item banking: item anchoring, ecological momentary assessment, and iterative re-calibration.

Chris Gibbons, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States

Symposium 4: Using PROs and Machine Learning to identify "at risk" patients for musculoskeletal injury

Meeting Room 6, Second Floor

Moderator:

Judith Baumhauer, MD, MPH, University of Rochester Medical Center, Rochester, NY, United States

Discussants:

David Mitten, MD, University of Rochester Medical Center, Rochester, NY, United States

Kostantinos Vasalos PT, CSCS, MSBA, University of Rochester Medical Center, Rochester, NY, United States

Submitted on behalf of University of Rochester Medical Center

Each year approximately 30-40% of people over the age of 65 fall. Approximately one half of these falls result in an injury with the estimated annual direct medical costs of \$30 billion. Equally devastating are osteoporotic fractures resulting in medical treatment costs of 15 billion dollars yearly. Identifying patients at risk to fall or to have osteoporosis with common tests and implementing a prevention plan would help patients and save cost to the healthcare system. Using real-time PRO data, electronic health data elements, structured physical examinations, and data analytics through machine learning, "at risk" patients can be identified and a further identification and preventative program put in place to decrease injury. Objective: To present: 1) the current standard of care PRO collection across a healthcare system at 3 years (185,000 unique patients); 2) the process and challenges using machine learning data analytics in defining "at risk" individuals for falls, osteoporosis and the need for skilled nursing after joint replacement; and 3) identifying preventative program selection or next steps discussions with clinicians.

Individual Presenters:

Standard of Care PRO Collection Across a Healthcare System

Paul Rubery, MD, University of Rochester Medical Center, Rochester, NY, United States

Does the Patient Reported Outcome Information System (PROMIS) Physical Function Scale Perform as Well as Recommended Performance Based Tests to Identify Older Adults at Falls Risk?

Jeff Houck, PT, PhD, George Fox University/University of Rochester, Newberg, OR, United States

Identifying Joint Replacement Patients at Risk for Skilled Nursing Facility (SNF) Placement using Computer Analytics and Neural Network Processing

Allison W. McIntyre, MPH, University of Rochester Medical Center, Rochester, NY, United States

Identifying Patients at Risk for Osteoporosis Using Artificial Intelligence on X-rays

David Mitten, MD, University of Rochester Medical Center, Rochester, NY, United States

Identifying Foot and Ankle Patients at Risk to Fall Based on Patient Reported Outcome Assessments

Kathleen Fear, PhD, University of Rochester Medical Center, Rochester, NY, United States

12:30 pm - 2:00 pm Buffet Lunch Break

Sussex Restaurant, Ground Floor

12:30 pm - 1:15 pm First Lunch Shift

1:15 pm - 2:00 pm Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Sussex Restaurant on the Ground Floor. Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. Entry into the restaurant is by name badge.

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12:35 pm – 1:30 pm Special Interest Group (SIG) Meetings

Australia and New Zealand SIG	Meeting Room 5
Canada PRO SIG Meeting	Meeting Room 6
Psychometrics SIG Meeting	Pembroke & Herbert
United Kingdom/Ireland SIG Meeting	Meeting Room 9

2:00 pm – 3:30 pm Concurrent Oral Sessions

Oral Session 201: Response Shift Meeting Room 1+2, Second Floor

Session Chair: Bruce Rapkin, PhD, United States

2:05 pm – 2:22 pm (201.1) Exploring Response shift recalibration using survival analysis

Mohamed Boucekine, PhD, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France; Anderson Loundou, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France; Laurent Boyer, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France; Jean Pelletier, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France; Karine Baumstarck, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France; Badih Ghattas, Department of Mathematics, Faculté des Sciences de Luminy, Aix-Marseille University, Marseille, France; Pascal Auquier, Aix-Marseille Université, EA 3279 Santé Publique et Maladies Chroniques, Marseille, France

2:23 pm – 2:40 pm (201.2) Evaluation of an algorithm to identify response shift and its determinants at the item level using Rasch family models – A simulation study

Priscilla Brisson, U1246 SPHERE - Université de Nantes, Nantes, France; Véronique Sébille, U1246 SPHERE - Université de Nantes, Nantes, France; Jean-Benoit Hardouin, U1246 SPHERE - Université de Nantes, Nantes, France; Myriam Blanchin, U1246 SPHERE - Université de Nantes, Nantes, France

2:41 pm – 2:58 pm (201.3) A critical appraisal of the Minimally Important Difference: Evidence of instability over time and across groups

Joel Finkelstein, M.D., M.Sc., FRCS(C), Sunnybrook Health Sciences Centre, Toronto, Ontario, Canada; Jie Zhang, M.P.H., DeltaQuest Foundation, Inc., Concord, MA, United States; Bruce Rapkin, Ph.D., Albert Einstein College of Medicine, Bronx, NY, United States; Carolyn Schwartz, Sc.D., DeltaQuest Foundation, Inc., Concord, MA, United States

2:59 pm – 3:16 pm (201.4) The implacability of item-response-theory measures: Does appraisal still impact interpretation of change?

Carolyn Schwartz, ScD, DeltaQuest Foundation, Inc., Concord, MA, United States; Jie Zhang, M.P.H., DeltaQuest Foundation, Inc., Concord, MA, United States; Wesley Michael, M.B.A., Rare Patient Voice, LLC, Towson, MD, United States; Bruce Rapkin, Ph.D., Albert Einstein School of Medicine, Bronx, NY, United States

Oral Session 202: Meeting the Needs of Stakeholders Meeting Room 6, Second Floor

Session Chair: Angela Stover, PhD, United States

2:05 pm – 2:22 pm (202.1) Embedding patient and public involvement within the Centre for Patient Reported Outcomes Research

Olalekan Lee Aiyegbusi, MBChB, MPH, Centre for Patient-Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Grace Turner, PhD, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Derek Kyte, PhD, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Anita Slade, PhD, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Magdalena Skrybant, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Gary Price, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom; Melanie Clavert, PhD, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, University of Birmingham, Birmingham, United Kingdom

2:23 pm – 2:40 pm (202.2) Strengthening scale development for clinical practice: recommendations for the next decade

Skye Barbic, University of British Columbia, West Vancouver, British Columbia, Canada; Jeremy Hobart, MD, Plymouth University, Plymouth, United Kingdom; David Barbic, MD, University of British Columbia, Vancouver, British Columbia, Canada; Susan Bartlett, PhD, McGill University, Montreal, Quebec, Canada; Clifton Bingham, MD, Johns Hopkins, Baltimore, United Kingdom; Steve Mathias, MD, University of British Columbia, Vancouver, British Columbia, Canada

2:41 pm – 2:58 pm (202.3) Common Issues Encountered in Regulatory Review of the Development of Clinical Outcome Assessments

Wen-Hung Chen, FDA, Silver Spring, MD, United States

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2:59 pm – 3:16 pm (202.4) Can Patient-Reported Outcomes Assessment Be Brought to Scale? Lessons from a Statewide PRO-focused Quality Improvement Initiative

Sara Khor, MASc, University of Washington, Seattle, WA, United States; Heather Harris, University of Washington, Seattle, WA, United States; David R. Flum, MD, MPH, University of Washington, Seattle, WA, United States; Amy M. Cizik, PhD, MS, University of Washington, Seattle, WA, United States; **Danielle C. Lavallee, PharmD, PhD, University of Washington, Seattle, WA, United States**

Oral Session 203: Clinical Trial Methods

Pembroke & Herbert, Ground Floor

Session Chair: Kathryn Flynn, PhD, United States

2:05 pm – 2:22 pm (203.1) Sample estimation for Randomised Controlled Trials with repeated assessment of Quality of Life: what correlation between baseline and follow up outcomes should we assume?

Stephen Walters, PhD, University of Sheffield, Sheffield, United Kingdom; Richard Jacques, PhD, University of Sheffield, Sheffield, United Kingdom; Mica Teo Shu Xian, University of Edinburgh, Edinburgh, United Kingdom

2:23 pm – 2:40 pm (203.2) Time to health-related quality of life score deterioration in oncology phase III clinical trials: a systematic review

Emilie Charton, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Fabio Efficace, PhD, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Francesco Cottone, PhD, Data Center and Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Célia Touraine, PhD, Montpellier Cancer Institute (ICM) – Val d'Aurelle, University of Montpellier, Montpellier, France; Benjamin Cuer, PhD Student, Montpellier Cancer Institute (ICM) – Val d'Aurelle, University of Montpellier, Institute of Cancer Research of Montpellier (IRCM), ICM, INSERM, Montpellier, France; Zeinab Hamidou, PhD, EA3279 Self-perceived Health Assessment Research Unit, Aix-Marseille University, French National Platform Quality of Life and Cancer, Marseille, France; Frédéric Fiteni, MD PhD, Department of Medical Oncology, University Hospital of Nimes, Montpellier Cancer Institute (ICM) – Val d'Aurelle, University of Montpellier, Nimes, France; Franck Bonnetain, PhD, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, French National Platform Quality of Life and Cancer, Besançon, France; Caroline Bascoul-Mollevi, PhD, Montpellier Cancer Institute (ICM) – Val d'Aurelle, University of Montpellier, Institute of Cancer Research of Montpellier (IRCM), ICM, INSERM, French National Platform Quality of Life and Cancer, Montpellier, France; Amélie Anota, PhD, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, French National Platform Quality of Life and Cancer, Besançon, France

2:41 pm – 2:58 pm (203.3) Systematic evaluation of patient-reported outcome (PRO) protocol content and reporting in cancer clinical trials: the EPiC study

Derek Kyte, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; Ameeta Retzer, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; Khaled Ahmed, University of Birmingham, Birmingham, United Kingdom; Thomas Keeley, GlaxoSmithKline (formerly of CPROR, University of Birmingham), London, United Kingdom; Jo Armes, School of Health Sciences, University of Surrey, Guildford, United Kingdom; Julia M Brown, UKCRC Registered CTU Network, University of Leeds, Leeds, United Kingdom; Lynn Calman, Macmillan Survivorship Research Group, Health Sciences, University of Southampton, Southampton, United Kingdom; Fabio Efficace, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA), Rome, Italy; Anna Gavin, N. Ireland Cancer Registry, Queen's University Belfast, Centre for Public Health, Belfast, United Kingdom; Adam Glaser, Leeds Institute of Cancer & Pathology, University of Leeds, Leeds, United Kingdom; Diana M Greenfield, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom; Anne Lanceley, UCL EGA Institute for Women's Health, University College London, London, United Kingdom; Rachel M Taylor, Cancer Division, University College Hospitals NHS Foundation Trust, London, United Kingdom; Galina Velikova, Leeds Institute of Cancer & Pathology, University of Leeds, Leeds, United Kingdom; Michael Brundage, Queen's Department of Oncology School of Medicine, Queen's University Cancer Research Institute, Kingston, Ontario, Canada; Rebecca Mercieca-Bebber, Central Clinical School, Sydney Medical School, University of Sydney, Sydney, Ontario, Australia; Madeleine T King, Psycho-Oncology Cooperative Research Group, Faculty of Science, University of Sydney, Sydney, Australia; Grace Turner, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; Melanie Calvert, Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

Scientific Program — Friday, 26 October

2:59 pm – 3:16 pm (203.4) Improving standards of patient reported outcomes analysis: developing a consensus taxonomy of key research objectives – a SISAQOL initiative

Madeline Pe, PhD, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Lien Dorme, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Corneel Coens, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Ethan Basch, Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, NC, United States; Melanie Calvert, Centre for Patient Reported Outcomes Research, Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham, United Kingdom; Alicyn Campbell, Genentech, San Francisco, CA, United States; Charles Cleeland, Department of Symptom Research, The University of Texas MD Anderson Cancer Center, Houston TX, United States; Kim Cocks, Adelphi Values, Bollington, Cheshire, United Kingdom; Laurence Collette, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Nancy Devlin, Office of Health Economics, London, United Kingdom; Amylou Dueck, Alliance Statistics and Data Center, Mayo Clinic, Scottsdale, AZ, United States; Hans-Henning Flechtner, Clinic for Child and Adolescent Psychiatry and Psychotherapy, University of Magdeburg, Magdeburg, Germany; Carolyn Gotay, School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada; Eva Greimel, Obstetrics and Gynecology, Medical University Graz, Graz, Austria; Ingolf Griebsch, Boehringer Ingelheim, Frankfurt, Germany; Mogens Groenvold, Department of Public Health and Bispebjerg Hospital, University of Copenhagen, Copenhagen, Denmark; Jean-Francois Hamel, Methodology and Biostatistics Department, University Hospital of Angers UNAM, Angers, France; Laura Lee Johnson, US Food and Drug Administration, Silver Spring, MD, United States; Madeleine King, School of Psychology and Sydney Medical School, University of Sydney, Sydney, Australia; Paul Kluetz, US Food and Drug Administration, Silver Spring, MD, United States; Michael Koller, Center for Clinical Studies, University Hospital Regensburg, Regensburg, Germany; Daniel Malone, College of Pharmacy, University of Arizona, Tucson, AZ, United States; Francesca Martinelli, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Sandra Mitchell, Outcomes Research Branch, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, United States; Jammbe Musoro, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; Daniel O' Connor, Medicines and Healthcare Products Regulatory Agency, London, United Kingdom; Kathy Oliver, International Brain Tumour Alliance, Surrey, United Kingdom; Elisabeth Piau-Louis, Genentech, San Francisco, CA, United States; Martine Piccart, Institut Jules Bordet, Université Libre de Bruxelles (ULB), Brussels, Belgium; Francisco Pimentel, Blueclinical Phase I, Porto, Portugal; Chantal Quinten, European Centre for Disease Prevention and Control, Surveillance and Response Support Unit, Epidemiological Methods: Section, Stockholm, Sweden; Jaap Reijneveld, VU University Medical Center, Department of Neurology & Brain Tumor Center, Amsterdam, Netherlands; Christoph Schurmann, Institute for Quality and Efficiency in Health Care, Cologne, Germany; Jeff Sloan, Alliance Statistics and Data Center, Mayo Clinic, Rochester, MN, United States; Ashley Wilder Smith, Outcomes Research Branch, Healthcare Delivery Research Program, Division of Cancer Control and Population Sciences, National Cancer Institute, Bethesda, MD, United States; Katherine Soltys, Health Canada, Ottawa, Ontario, Canada; Rajeshwari Sridhara, US Food and Drug Administration, Silver Spring, MD, United States; Martin Taphoorn, Leiden University Medical Center/Haaglanden Medical Center, Leiden/The Hague, Netherlands; Galina Velikova, Leeds Institute of Cancer and Pathology, University of Leeds, St James's Hospital, Leeds, United Kingdom; Andrew Bottomley, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium; submitted on behalf of Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) Consortium

NEW INVESTIGATOR ORAL PRESENTATION AWARD FINALIST

Oral Session 204: Underresearched Populations

Meeting Room 9, Second Floor

Session Chair: Kara L. Schick-Makaroff, PhD, RN, Canada

2:05 pm – 2:22 pm (204.1) Screening Strategy to Support Children at Risk - a technology-enabled catalyst for support

Nancy Young, BSCT MSc PhD, Laurentian University, Sudbury, Ontario, Canada; Diane Jacko, BA, Naandeweichige-Gamig Wikemikong Health Centre, Wiikwemkoong Unceded Territory, Ontario, Canada; Marnie Anderson, BPHE, Laurentian University, Sudbury, Ontario, Canada; Trisha Trudeau, BA, Naandeweichige-Gamig Wikemikong Health Centre, Wiikwemkoong Unceded Territory, Ontario, Canada; Koyo Usuba, MHK, Laurentian University, Sudbury, Ontario, Canada; Mary Jo Wabano, MHK, Naandeweichige-Gamig Wikemikong Health Centre, Wiikwemkoong Unceded Territory, Ontario, Canada

2:23 pm – 2:40 pm (204.2) Older patients going through kidney transplantation – Results: from a large, prospective multi Methods: study

Kjersti Lønning, RN, PhD student, Department of Transplantation Medicine, Oslo University Hospital, Oslo, Norway; Karsten Midtvedt, MD PhD, Department of Transplantation Medicine, Oslo University Hospital, Oslo, Norway; Kristian Heldal, MD PhD, Clinic of Internal Medicine, Telemark Hospital Trust, Skien, Norway; Marit Helen Andersen, RN PhD, Department of Transplantation Medicine, Oslo, Norway

2:41 pm – 2:58 pm (204.3) Building a rare disease research consortium with harmonized, patient-powered natural history registries

Vanessa Boulanger, MSc, National Organization for Rare Disorders, Danbury, CT, United States; Allison Seebald, National Organization for Rare Disorders, Danbury, CT, United States; Suzanne Rossov, National Organization for Rare Disorders, Danbury, CT, United States

2:59 pm – 3:16 pm (204.4) A pragmatic patient-reported outcome strategy for rare disease clinical trials: Application of the EORTC Item Library to higher risk myelodysplastic syndromes, low-blast acute myeloid leukemia, chronic myelomonocytic leukemia

Jill A. Bell, Takeda Pharmaceuticals, Cambridge, MA, United States; Aaron Galaznik, MD, Takeda Pharmaceuticals, Millennium Pharmaceuticals, Cambridge, MA, United States; Farrah Pompilus, MA, Modus Outcomes, Cambridge, MA, United States; Sara Strzok, MA, Modus Outcomes, Cambridge, MA, United States; Robert J. Fram, MD, Takeda Pharmaceuticals, Millennium Pharmaceuticals, Cambridge, MA, United States; Douglas V. Faller, MD, PhD, Takeda Pharmaceuticals, Millennium Pharmaceuticals, Cambridge, MA, United States; Antoine Regnault, PhD, Modus Outcomes, Lyon MA, France; Stefan Cano, PhD, CPsychol, AFBPsS, Modus Outcomes, Cambridge, MA, United States; Patrick Marquis, MD, MBA, Modus Outcomes, Cambridge, MA, United States

Friday, 26 October

Scientific Program — Friday, 26 October

3:30 pm - 4:15 pm Exhibits Open and Refreshment Break Fitzwilliam Suites, Ground Floor

3:35 pm - 4:10 pm Friday Poster Session II Lansdowne Room, Ground Floor

Caregivers

(2010) An Evidence Map of Instruments for Caregiver Reported Outcomes

Cassie Springate, MSc PhD, Crystallise, Essex, United Kingdom

(2012) Romanian social workers' professional quality of life

Florin Lazar, University of Bucharest, Faculty of Sociology and Social Work, Bucharest, Romania; Shari Munch, Rutgers, The State University of New Jersey, School of Social Work, New Jersey, NY, United States; Adrian Luca, University of Bucharest, Psychology and Education, Bucharest, Romania; Daniela Gaba, University of Bucharest, Faculty of Sociology and Social Work, Bucharest, Romania; Anca Mihai, University of Bucharest, Faculty of Sociology and Social Work, Bucharest, Romania; Georgiana-Cristina Rentea, University of Bucharest, Faculty of Sociology and Social Work, Bucharest, Romania; Alexandra Ciocanel, University of Bucharest, Faculty of Sociology and Social Work, Bucharest, Romania; Marian Popa, University of Bucharest, Faculty of Psychology and Education, Bucharest, Romania

(2014) Evaluating the measurement properties of the Pediatric RSV Severity and Outcome Rating Scale (PRESORS) Clinician-Reported Outcome and Observer-Reported Outcome measures for assessing severity of pediatric Respiratory Syncytial Virus (RSV) infection

Christine de la Loge, Mapi, Bourgogne, France; Paul Williams, Mapi, Lyon, France; Sarah Rusch, Janssen Research and Development, Beerse, Belgium; Hein Fennema, Janssen Research and Development, Beerse, Belgium; David Rivas, Janssen Research & Development, Raritan, NJ, United States; Marita Stevens, Janssen Research and Development, Beerse, Belgium; Linda Abetz-Webb, Patient-Centred Outcomes Assessments Ltd, Macclesfield, United Kingdom; Jane Scott, Janssen Global Services, High Wycombe, United Kingdom

(2016) Impact of Caregiving on Caregiver Burden, Self-Efficacy, and Quality of Life among Hispanic Working Elder Caregivers

Lina Mayorga, MPH, CHES, Oncology Research + Education Consultants, Pasadena, CA, United States; Gloria Juarez, PhD, Oncology Research + Education Consultants, Pasadena, CA, United States; Joan Branin, PhD, Center for Health and Aging, Pasadena, CA, United States

(2018) Psychosocial Functioning in Parents of MPS III Patients

Lotte Haverman, Psychosocial department, Emma Children's Hospital, Amsterdam University Medical Centers, Amsterdam, Netherlands; Stephanie Nijmeijer, MD, Department of Pediatric Metabolic Diseases, Emma Children's Hospital and Lysosome Center Sphinx, Amsterdam University Medical Centers, Amsterdam, Netherlands; Thirsa Conijn, MSc, Department of Pediatric Metabolic Diseases, Emma Children's Hospital and Lysosome Center Sphinx, Amsterdam University Medical Centers, Amsterdam, Netherlands; Hedy van Oers, MSc, Psychosocial department, Emma Children's Hospital, Amsterdam University Medical Centers, Amsterdam, Netherlands; Frits Wijburg, prof. dr., Department of Pediatric Metabolic Diseases, Emma Children's Hospital and Lysosome Center Sphinx, Amsterdam University Medical Centers, Amsterdam, Netherlands

(2020) Health Related Quality of Life using EQ5D5L and the Burden of Care

Luke Barry, MSc, National University of Ireland, Galway, Galway, Ireland; Anna Hobbins, MSc, Queen's University Belfast, Belfast, United Kingdom; Daniel Kelleher, MSc, National University of Ireland, Galway, Galway, Ireland; Ciaran O'Neill, PhD, Queen's University Belfast, Belfast, United Kingdom

(2022) Impact of severe polyhandicap on parents' quality of life

Marie-Christine Rousseau, EA 3279 CERESS - Health Service Research and Quality of Life Center Aix-Marseille Univ, Marseille, France; Thierry Billette de Villemeur, Fédération des Hôpitaux de Polyhandicap et Multihandicap Hôpital San Salvador, Assistance Publique Hôpitaux de Paris, Paris, France; Sherezad Khalidi-Cherif, Union Générale Caisse Assurance Maladie (UGECAM), Paris, France; Agnes Felce, Hôpital d'Hendaye, Assistance Publique Hôpitaux de Paris, Hendaye, France; Catherine Brisse, Comité d'Études, d'Éducation et de Soins Auprès des Personnes Polyhandicapées, Paris, France; Anderson Loundou, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Benjamin Moheng, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Claire Morando, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Latif Aden, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Pascal Auquier, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Karine Baumstarck, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille Université, Marseille, France; Mohamed Boucekine, PhD, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille University, Marseille, France; Sarah Fernandes, MD, EA3279, Self-perceived Health Assessment Research Unit, Aix Marseille University, Marseille, France; submitted on behalf of French Polyhandicap Group

(2024) Predictors of Self-Reported Health Status among Childcare Workers in Alberta, Canada

Oluwabohunmi Awosoga, Faculty of Health Sciences, University of Lethbridge, Calgary, Alberta, Canada; Oluwaseyi Lawal, MSc, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Jon Doan, PhD, PEng, Department of Kinesiology & Physical Education, University of Lethbridge, Lethbridge, Alberta, Canada; Claudia Steinke, PhD, RN, Nursing, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Jarrod Blinch, PhD, Department of Kinesiology & Sports Management, Texas Tech University, Texas, TX, United States; Trish Provost, BSc, Department of Kinesiology & Physical Education, University of Lethbridge, Lethbridge, Alberta, Canada; Julia Dabravolskaj, MD, MSc, Edmonton Oliver Primary Care Network, Edmonton, Alberta, Canada; Tolupe Sajobi, PhD, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

(2026) Oncology: caring for the caregivers

Pedro Lopez Ferreira, CEISUC/FEUC, Coimbra, Portugal; Sara Amaral, MSc, UFP, Porto, Portugal; Francisco Pimentel, PhD, CEISUC, Porto, Portugal; Augusta Silveira, PhD, CEISUC/UFP, Porto, Portugal; Teresa Sequeira, PhD, CEISUC/UFP, Porto, Portugal

(2028) Quality of Life (QOL) Questionnaire for Mothers of Schoolchildren (part 2)

Rika Hayashida, University of Nagasaki, Siebold, Nishisonogi-gun, Nagasaki, Japan; Michiko Kobayashi, Japanese Society of Quality of Life Research, Kobe, Japan; Takashi Mandai, Japanese Society of Quality of Life Research, Kobe, Japan

(2030) Clinician (ClinRO) and Caregiver (ObsRO) reported severity assessments for respiratory syncytial virus (RSV) in infants and young children: Development and qualitative content validation of Pediatric RSV Severity and Outcome Rating Scales (PRESORS)

Jane Scott, Janssen Global Services, High Wycombe, United Kingdom; Sophi Tatlock, Adelphi Values Ltd, Bollington, United Kingdom; **Sarah Kilgariff, Adelphi Values Ltd, Bollington, United Kingdom;** Rob Arbuckle, Adelphi Values Ltd, Bollington, United Kingdom; Linda Abetz-Webb, Patient-Centered Outcomes Assessments Ltd, Bollington, United Kingdom; Sarah Rusch, Janssen Research and Development, Beerse, Belgium; Marita Steven, Janssen Research and Development, Beerse, Belgium

(2032) Wellbeing, health status and confidence of carers and those cared for in a GP practice

Tim Benson, R-Outcomes Ltd, Thatcham, United Kingdom; Charles Walker, MB ChB, Runnymede Medical Practice, Windsor, United Kingdom

(2034) Quality of life and marital satisfaction of family caregivers of patients with mental disorders

Douglas José Nogueira, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Ruth Minamisava, PhD, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Sandra Maria Brunini Souza, PhD, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Sheila Araujo Teles, PhD, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Jacqueline Andreia Bernardes Leão Cordeiro, PhD - Nursing, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; **Virginia Visconde Brasil, PhD - Nursing, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil;** Denise Soares Cirqueira, Master, Health Department of Goiânia, Goiania - Goiás, Brazil; Luiz Antonio Brasil, PhD in Medicine, Faculty of Medicine, Federal University of Goiás, Goiania - Goiás, Brazil; Ana Lúcia Rezende Souza, PhD, Federal University of Jataí, Jataí - Goiás, Brazil; Patrícia de Sá Barros, PhD, Federal University of Jataí, Jataí - Goiás, Brazil; Camila Cardoso Caixeta, PhD, Nursing, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Elizabeth Esperidião Cardozo, PhD, Nursing, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Lizete Malagone de Almeida Cavalcante Oliveira, PhD, Health Sciences, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil; Maria Alves Barbosa, PhD, Nursing, Nursing Faculty, Federal University of Goiás, Goiania - Goiás, Brazil

Dermatology

(2036) Atopic dermatitis: Development of a literature-based conceptual model and review of patient-, observer- and clinician-reported outcome measures

Cynthiya Ruban, PhD, MS, Xcenda, Tampa, FL, United States; **Somali Misra Burgess, PhD, Xcenda, Tampa, FL, United States**

(2038) New self-reported and proxy measures of pediatric itch interference

Dagmar Amtmann, University of Washington, Seattle, WA, United States; Kara McMullen, MPH, University of Washington, Seattle, WA, United States; Alyssa Bamer, MPH, University of Washington, Seattle, WA, United States; Rana Salem, MA, University of Washington, Seattle, WA, United States; Nicole Gibran, MD, University of Washington, Seattle, WA, United States; David Herndon, MD, University of Texas Medical Branch, Galveston, TX, United States; Karen Kowalske, MD, University of Texas Southwestern, Dallas, TX, United States; Walter Mayer, PhD, University of Texas Medical Branch, Galveston, TX, United States; Jeffrey C. Schneider, MD, Spaulding Rehabilitation Hospital, Boston, MA, United States; Mara Nery-Hurwit, PhD, MPH, University of Washington, Seattle, WA, United States

(2040) Development of a standard dataset for the documentation of psoriasis: a delphi approach with psoriasis experts

Marina Otten, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Marc Radtke, Prof. Dr., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Augustin, Prof. Dr., University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(2042) Measuring the impact of Atopic dermatitis on caregivers and families: results from a literature review

Nuzhat Afroz, Masters in health administration (MHA), Bachelor in dental surgery (BDS), Novartis healthcare private Limited, Hyderabad, India; Christel Naujoks, MSc (Econ), MPH, MHLthEcon, MBA, MAS HP (Health Promotion), Novartis Pharma AG, Basel, Switzerland, Basel, Switzerland; Francesco Patalano, MBBS, MD, Novartis Pharma AG, Basel, Switzerland, Basel, Switzerland; Isabelle Gilloteau, Msc. MPH, Novartis Pharma AG, Basel, Switzerland, Basel, Switzerland

(2044) Translating the WHO psoriasis resolution into the public: the German federal program against stigmatization 2018-2020

Rachel Sommer, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Augustin, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Claudia Luck-Sikorski, University of Applied Health Sciences Gera, Gera, Germany; Janine Topp, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ines Schaefer, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Marc-Alexander Radtke, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sophia Schlette, Berufsverband der Deutschen Dermatologen, Berlin, Germany; Natascha Weinberger, University of Applied Health Sciences Gera, Gera, Germany; Regina von Spreckelsen, University Medical Center Schleswig-Holstein, Kiel, Germany; Anja Hilbert, University Medical Center Leipzig, Leipzig, Germany; Alexander Zink, Technical University of Munich, Munich, Germany; Dagmar Wilsmann-Theis, University Medical Center Bonn, Bonn, Germany; Eckardt Breitbart, Dermatology Breitbart, Buxtehude, Germany; Ulrich Mrowietz, University Medical Center Schleswig-Holstein, Kiel, Germany

Hematology

(2046) Quantitative Testing of the Myelofibrosis Symptom Assessment Form Version 4.0: An Online Comparison Study with Legacy Myelofibrosis Symptom Questionnaires

Amylou Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; Wen-Hung Chen, Clinical Outcome Assessments Staff, Office of New Drugs, Center for Drug Evaluation and Research, U.S. Food and Drug Administration, Silver Spring, MD, United States; Sonya Eremenco, Patient-Reported Outcome Consortium, Critical Path Institute, Tucson, AZ, United States; Gina L Mazza, Mayo Clinic, Scottsdale, AZ, United States; Renee Pierson, Janssen Pharmaceuticals Inc, Raritan, NJ, United States; Lixia Wang, CTI BioPharma Corp, Seattle, WA, United States; Jeremiah Trudeau, Janssen Pharmaceuticals Inc, Raritan, NJ, United States; Chad Gwaltney, Gwaltney Consulting and Brown University, Westerly, RI, United States; Stephen Joel Coons, Patient-Reported Outcome Consortium, Critical Path Institute, Tucson, AZ, United States; Ruben A Mesa, Mays Cancer Center at UT Health San Antonio MD Anderson, San Antonio, TX, United States

(2048) Health-related quality of life in multiple myeloma patients with first relapse treated with Carfilzomib-based re-induction and salvage autologous stem cell transplantation: data from a Nordic phase II trial

Henrik Rode Eshoj, PT, PhD, Quality of Life Research Center, Department of Hematology, Odense University Hospital and OPEN Odense Patient data Explorative Network, Odense University Hospital, Odense, Denmark; Lene Kongsgaard Nielsen, MD, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark; Fredrik Schjesvold, MD, Department of Hematology, Oslo University Hospital, Oslo, Norway; Niels Abildgaard, MD, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark; Hareth Nahi, MD, Department of Hematology, Karolinska University Hospital, Stockholm, Sweden; Niels Frost Andersen, MD, Department of Hematology, Aarhus University Hospital, Aarhus, Denmark; Annette Juul Vangsted, MD, Department of Hematology, Rigshospitalet, Copenhagen, Denmark; Carsten Helleberg, MD, Department of Hematology, Herlev Hospital, Herlev, Denmark; Ulf Christian Frølund, MD, Department of Hematology, Zealand University Hospital, Roskilde, Denmark; Per Axelsson, MD, Department of Hematology, Helsingborg Hospital, Helsingborg, Sweden; Olga Stromberg, MD, Department of Hematology, Karolinska University Hospital, Stockholm, Sweden; Cecilie Blimark, MD, Department of Hematology, Sahlgrenska University Hospital, Göteborg, Sweden; Kristina Carlson, MD, Department of Hematology, Uppsala University Hospital, Uppsala, Sweden; Anders Waage, MD, Department of Hematology, St Olavs hospital/NTNU, Trondheim, Norway; Kari Remes, MD, Department of Hematology, Turku University Hospital, Turku, Finland; Valdas Peceliunas, MD, Department of Hematology, Vilnius University Hospital, Vilnius, Lithuania; Nina Guldbrandsen, MD, Department of Hematology, Oslo University Hospital, Oslo, Norway; Markus Hansson, MD, Department of Hematology, Skåne University Hospital, Lund, Sweden; Henrik Gregersen, MD, Department of Hematology, Aalborg University Hospital, Aalborg, Denmark

(2050) Impacts of cognitive and behavioral problems on family financial hardship in survivors of pediatric acute lymphoblastic leukemia

I-Chan Huang, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Larry Mullins, PhD, Oklahoma State University, Stillwater, OK, United States; Leslie Robison, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States; Ching-Hon Pui, MD, St. Jude Children's Research Hospital, Memphis, TN, United States; Melissa Hudson, MD, St. Jude Children's Research Hospital, Memphis, TN, United States; Kevin Krull, PhD, St. Jude Children's Research Hospital, Memphis, TN, United States

(2052) Health-related quality of life and physical activity in patients with multiple myeloma in remission

Lene Kongsgaard Nielsen, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark; Rikke Faebo Larsen, Physiotherapist, PhD student, Department of Occupational Therapy and Physiotherapy Haematology, Zealand University Hospital, Roskilde, Denmark; Eva Jespersen, Physiotherapist, PhD, Post.doc, Department of Rehabilitation, Odense University Hospital, Institute of Clinical Research, University of Southern Denmark and REHPA - The Danish Knowledge Centre for Rehabilitation and Palliative Care, Institute of Clinical Research, University of Southern, Odense, Denmark

(2054) Comparison of the measurement properties of paper and electronic version of HM-PRO, a new patient-reported outcome measure for use in patients with haematological malignancies: An equivalence study

Pushpendra Goswami, PhD, School of Life and Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom; Esther N Oliva, Haematology Unit, Grande Ospedale Metropolitano, Reggio Calabria, Italy; Tatyana Ionova, University Clinic, St.Petersburg State University and Multinational Centre for Quality of Life Research, Saint-Petersburg, Russia; Roger Else, Patient Research Partner, Milton Keynes, United Kingdom; Jonathan Kell, Cardiff and Vale University Health Board, Cardiff, United Kingdom; Adele K Fielding, University College London, Cancer Institute, London, United Kingdom; Daniel M Jennings, Royal Surrey County Hospital NHS Foundation Trust, Guildford, Surrey, United Kingdom; Marina Karakantza, Leeds teaching Hospital NHS Trust, Leeds, United Kingdom; Saad Al-Ismael, Singleton Hospital, ABM University Health Board, Swansea, United Kingdom; Graham P Collins, Oxford University Hospitals NHS Trust, Oxford, United Kingdom; Stewart McConnell, Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom; Catherine Langton, Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom; Magda Jabbar Al-Obaidi, West Middlesex University Hospital, Isleworth, United Kingdom; **Sam Salek, School of Life & Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom**

(2056) Impact of past and present chronic graft-versus-host disease on quality of life in hematopoietic cell transplantation survivors

Saiko Kurosawa, MD, National Cancer Center Hospital, Tokyo, Japan; Takuhiro Yamaguchi, Tohoku University Graduate School of Medicine, Sendai, Japan; Kumi Oshima, Jyoban Hospital, Tokiwa Foundation, Fukushima, Japan; Atsumi Yanagisawa, Japanese Data Center for Hematopoietic Cell Transplantation, Nagoya, Japan; Takahiro Fukuda, National Cancer Center Hospital, Tokyo, Japan; Heiwa Kanamori, Kanagawa Cancer Center, Yokohama, Japan; Takehiko Mori, Keio University School of Medicine, Tokyo, Japan; Satoshi Takahashi, Institute of Medical Science, University of Tokyo, Tokyo, Japan; Tadakazu Kondo, Kyoto University, Kyoto, Japan; Megumi Oi, JA Aichi Konan Kosei Hospital, Konan, Japan; Koichi Miyamura, Japanese Red Cross Nagoya First Hospital, Nagoya, Japan; Yukari Umemoto, Osaka City University, Osaka, Japan; Takanori Teshima, Hokkaido University Graduate School of Medicine, Sapporo, Japan; Shuichi Taniguchi, Toranomon Hospital, Tokyo, Japan; Takuya Yamashita, St. Luke's International Hospital, Tokyo, Japan; Yoshihiro Inamoto, National Cancer Center Hospital, Tokyo, Japan; Yoshinobu Kanda, Jichi Medical University, Tochigi, Japan; Shinichiro Okamoto, Keio University School of Medicine, Tokyo, Japan; Yoshiko Atsuta, Japanese Data Center for Hematopoietic Cell Transplantation, Nagoya, Japan

Immunology

(2058) Psychometric Evaluation of the Immunoglobulin Patient Experience With Treatment (IgPET) in Primary Immunodeficiency Diseases

Theresa Coles, RTI- Health Solutions, Research Triangle Park, NC, United States; Lisa M. Meckley, Shire Plc, Cambridge, MA, United States; **Lori McLeod, RTI- Health Solutions, Research Triangle Park, NC, United States**; Nikki Williams, RTI- Health Solutions, Research Triangle Park, NC, United States; Dana DiBenedetti, RTI- Health Solutions, Research Triangle Park, NC, United States; Giovanna Devercelli, Shire Plc, Cambridge, MA, United States

(2060) Quality of life in patients with cutaneous lupus erythematosus (CLE): validation of generic and disease-specific measures

Motolani Ogunsanya, B.Pharm, PhD, College of Pharmacy, University of Oklahoma Health Sciences Center, Oklahoma City, OK, United States; Andrew Hudson, Department of Dermatology, University of Texas Southwestern Medical Center, Dallas, TX, United States; Rebecca Vasquez, MD, Department of Dermatology, University of Texas Southwestern Medical Center, Dallas, TX, United States; Benjamin Chong, MD, Department of Dermatology, University of Texas Southwestern Medical Center, Dallas, TX, United States

Mental Health

(2062) "The coming of age of the SQLS-R4" - A culmination of twenty years of development, validation and translation of a schizophrenia clinical outcome assessment.

Adelina Lear, BA (Hons), ICON PLC, Didcot, United Kingdom; Diane Wild, Oxford, United Kingdom

(2064) Psychometric qualities of anger scale applied to persons with or without mental illness in Taiwan

Ay Woan Pan, PhD, School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan; Tsyr-Jang Chen, PhD, Department of Mechanical Engineering, LungHwa University of Science and Technology, Taoyuan, Taiwan

(2066) Differentiating coping behaviors in predicting NIH Toolbox Psychological Well-Being

Elizabeth Dworak, BA, Northwestern University, Evanston, IL, United States; Robert Chapman, Northwestern University, Chicago, IL, United States; David Condon, Ph.D., M.S., M.B.A., Northwestern University, Chicago, IL, United States

(2068) Does Sense of Coherence buffer acute mental stress in older people?

Junko Sakano, Ph.D., Okayama Prefectural University, Okayama, Japan; Yoichi Sawada, Ph.D., Okayama Prefectural University, Okayama, Japan; Yuki Yajima, Ph.D., Niimi College, Okayama, Japan; Atsushi Ueda, Okayama Prefectural University, Okayama, Japan

(2070) Anxiety, Depression, and Fertility-Specific Quality of Life Among Couples Experiencing Infertility

Rachel Cusatis, PhD, Medical College of Wisconsin, Milwaukee, WI, United States; Nicole Fergestrom, MS, Medical College of Wisconsin, Milwaukee, WI, United States; Abbey Kruper, PsyD, Medical College of Wisconsin, Milwaukee, WI, United States; Kate Schoyer, MD, Medical College of Wisconsin, Milwaukee, WI, United States; Kathryn E. Flynn, PhD, Medical College of Wisconsin, Milwaukee, WI, United States

(2072) Quality of work life and mental health in primary care physicians in Guadalajara, Mexico.

Raquel González-Baltazar, University of Guadalajara, Guadalajara, Jalisco, Mexico; Silvia G. León-Cortés, PhD, University of Guadalajara, Guadalajara, Mexico; Mónica I. Contreras-Estrada, PhD, University of Guadalajara, Guadalajara, Mexico; Brenda J. Hidalgo-González, Especialidad in Gestalt Psychotherapy, University of Guadalajara, Guadalajara, Mexico; Gustavo Hidalgo-Santacruz, Master, University of Guadalajara, Guadalajara, Mexico

(2074) A mixed methods approach to developing and testing the Canadian Personal Recovery Outcome Measure (C-PROM)

Skye Barbic, University of British Columbia, West Vancouver, British Columbia, Canada

Nephrology/Kidney Disease

(2076) Key health items in self-report instruments used among solid organ transplant recipients

Ahmad Shahabeddin Parizi, MD-MPH, Department of Epidemiology - University medical center Groningen, Groningen, Netherlands; Paul F.M. Krabbe, PhD, Department of Epidemiology - University medical center Groningen, Groningen, Netherlands; Erik Buskens, MD-PhD, Department of Epidemiology - University medical center Groningen, Groningen, Netherlands; Stephan J.L. Bakker, MD-PhD, Department of Internal Medicine - University medical center Groningen, Groningen, Netherlands; Karin M. Vermeulen, PhD, Department of Epidemiology - University medical center Groningen, Groningen, Netherlands

(2078) Tele follow-up using Patient-reported Outcomes (PRO) measures in patients with chronic kidney disease - the PRO-KID study: A study protocol for a non-inferiority randomised controlled trial in Denmark

Birgith Grove, MHSc, AmbuFlex, Herning, Denmark; Per Ivarsen, MD, PhD, Department of Nephrology, Aarhus University Hospital, Aarhus, Denmark; Annette De Thurah, MPH, PhD, Department of Rheumatology, Aarhus University Hospital, Aarhus, Denmark; Derek Kyte, PhD, Centre for Patient-Reported Outcomes Research, Birmingham, United Kingdom; Hjøllund Niels Henrik, MD, Professor, AmbuFlex/WestChronic, Occupational Medicine, Herning, Denmark

(2080) Standardised outcomes in nephrology (SONG): Establishing a core fatigue patient-reported outcome measure for trials in haemodialysis

Angela Ju, The University of Sydney, Sydney, Australia; Mark Unruh, Division of Nephrology, University of New Mexico School of Medicine, Albuquerque, NM, United States; Jonathan Craig, Centre for Kidney Research, Sydney, Australia; Allison Tong, Centre for Kidney Research, Sydney, Australia; **Claudia Rutherford, The University of Sydney, Sydney, Australia**

(2082) Symptoms, Coping and Quality of Life for People with Chronic Kidney Disease

Kara Schick-Makaroff, University of Alberta, Edmonton, Alberta, Canada; Anita Molzahn, PhD, RN, FCAHS, University of Alberta, Sidney, British Columbia, Canada; Mary Kalfoss, DrPH, MA, BScN, RN, VID Specialized University, Oslo, Norway

(2084) Evaluation of quality of life changes in patients on waiting list for kidney transplantation using growth mixture models coupled with latent class analysis.

Line Enjalbert, Hospital University of Nantes, University of Nantes, University of Tours, INSERM, Nantes, France; Jean-Benoit Hardouin, PhD, University of Nantes, University of Tours, INSERM, Nantes, France; Myriam Blanchin, University of Nantes, University of Tours, INSERM, Nantes, France; Magali Giral, Hospital University of Nantes, INSERM, Nantes, France; Aurélie Meurette, Hospital University of Nantes, Nantes, France; Véronique Sébille, ScD, University of Nantes, University of Tours, INSERM, Nantes, France

Paediatrics

(2086) Risk and protective factors of health-related quality of life in children and adolescents: results of the longitudinal BELLA study

Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Anne-Catherine Haller, Dipl Psych, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Fionna Klases, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Franziska Reiß, Dipl Soz, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Monika Bullinger, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Ulrike Ravens-Sieberer, PhD, MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

(2088) Interventions to improve participation and quality of life in children with visual impairment: a systematic review

Ellen Elsman, PhD Student, Amsterdam University Medical Centers, location VUmc, dept. of Ophthalmology, Amsterdam, Netherlands; Mo Al Baaj, VU University Medical Centre, dept. of Ophthalmology, Amsterdam, Netherlands; Ger van Rens, VU University Medical Centre, dept. of Ophthalmology, Amsterdam, Netherlands; Hilde van der Aa, VU University Medical Centre, dept. of Ophthalmology, Amsterdam, Netherlands; Martijn Heymans, VU University Medical Centre, dept. of Epidemiology and Biostatistics, Amsterdam, Netherlands; Ralph de Vries, Vrije Universiteit, Medical Library, Amsterdam, Netherlands; Mathijs Vervloed, Radboud University, Behavioral Science Institute, Nijmegen, Netherlands; Bert Steenberg, Radboud University, Behavioral Science Institute, Nijmegen, Netherlands; Ruth van Nispen, VU University Medical Centre, Amsterdam, Netherlands

(2090) Attributes associated with quality of life of transsexual children and adolescents in Latin America

Fernanda Karla Nascimento, Bachelor of nursing, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Valeria Andrade, Master, Federal University of Triângulo Mineiro, Uberaba, Brazil; Viviane Romeiro, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Beatriz Conacci, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Monica Mombelli, Master, Centro Universitário União Dinâmica das Cataratas, Foz do Iguaçu, Brazil; **Claudia Benedita dos Santos, Doctor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil**

(2092) Identifying the most suitable quality of life assessment measures to assess humanistic burden of acute otitis media in children

Garima Sharma, Novartis Healthcare Private Limited, Hyderabad, India; Christel Naujoks, Novartis Pharma AG, Basel, Switzerland; Francesco Patalano, Novartis Pharma AG, Basel, Switzerland; Brigitte Sloesen, Novartis Pharma AG, Basel, Switzerland; Daniel Viriato, Novartis Pharma AG, Basel, Switzerland

(2094) Withdrawn

(2096) Validation of new Patient Reported Outcome Measurement Information System (PROMIS) measures in children with sickle cell disease

Ashima Singh, PhD, Medical College of Wisconsin, Milwaukee, WI, United States; Mahua Dasgupta, MS, Medical College of Wisconsin, Milwaukee, WI, United States; Pippa Simpson, PhD, Medical College of Wisconsin, Milwaukee, WI, United States; **Julie Panepinto, MD, MSPH, Medical College of Wisconsin, Milwaukee, WI, United States**

(2098) CLEFT-Q: Detecting differences in outcomes between 2,434 patients with varying cleft types.

Karen Wong Riff, MD PhD FRCS, Hospital for Sick Children, Toronto, Ontario, Canada; Elena Tsangaris, PhD, Harvard University, Boston, MA, United States; Christopher R. Forrest, MD MSc FRCS, Hospital for Sick Children, Toronto, Ontario, Canada; Tim Goodacre, FRCS BSc MBBS, Oxford University Hospitals, Oxford, United Kingdom; Natasha M. Longmire, BHSc MSc, McMaster University, Hamilton, Ontario, Canada; Gregory Allen, MD FAAP FACS, University of Colorado, Aurora, CO, United States; Douglas J. Courtemanche, MD MS FRCS, University of British Columbia, Vancouver, British Columbia, Canada; Jesse Goldstein, MD FACS FAAP, Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA, United States; Aisling O'Mahony, MA FDS DDS, St. James' Hospital, Dublin, Ireland; Andrea Pusic, MD MSc FRCS, Harvard University, Boston, MA, United States; Rona Slator, FRCS FRCS(Plast) DPhil, Birmingham Children's Hospital, Birmingham, United Kingdom; Marc C. Swan, DPhil FRCS(Plast), Oxford University Hospitals, Oxford, United Kingdom; Achilleas Thoma, MD MSc FRCS, McMaster University, Hamilton, Ontario, Canada; Federico Vargas, MD, Universidad el Bosque, Bogota, Colombia; Anne F. Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada

(2100) The Infant health-related Quality of life Instrument (IQI): Valuing health status in the first year of life

Karin M. Vermeulen, PhD, University of Groningen, University Medical Center Groningen, Groningen, Netherlands; Ruslan Jabrayilov, PhD, University of Groningen, University Medical Center Groningen, Groningen, Netherlands; Livia Dainelli, PhD, Nestlé Research Center, Lausanne, Switzerland; Patrick Detzel, PhD, Nestlé Research Center, Lausanne, Switzerland; Antoinette D.I. van Asselt, PhD, University of Groningen, University Medical Center Groningen, Groningen, Netherlands; Paul F.M. Krabbe, PhD, University of Groningen, University Medical Center Groningen, Groningen, Netherlands

(2102) Associations between children's social-emotional functioning at school entry and future social connectedness and subjective well-being in middle childhood

Kimberly Thomson, University of British Columbia, Vancouver, British Columbia, Canada; Chris Richardson, University of British Columbia, Vancouver, British Columbia, Canada; Jean Shoveller, University of British Columbia, Vancouver, British Columbia, Canada; Martin Guhn, University of British Columbia, Vancouver, British Columbia, Canada; **Anne Gadermann, PhD, Human Early Learning Partnership, University of British Columbia, Vancouver, British Columbia, Canada**

(2104) Confirmatory factor analysis of KIDSCREEN-27 in young schoolchildren and relationships between health-related quality of life dimensions and body mass index and physical activity

Kirsti Riiser, PhD, Oslo Metropolitan University, Oslo, Norway; Knut-Andreas Christophersen, PhD, University of Oslo, Oslo, Norway; Kirstin Haraldstad, PhD, University of Agder, Kristiansand, Norway; Sølvi Helseth, PhD, Oslo Metropolitan University, Oslo, Norway

(2106) Determinants of Health-related Quality of Life: Comparison of empirically-derived models from Brazilian and Canadian boys with haemophilia in clinical practice

Koyo Usuba, Master in Human Kinetics, Laurentian University, Sudbury, Ontario, Canada; Nancy Young, PhD, Laurentian University, Sudbury, Ontario, Canada; Victor Blanchette, MD, The Hospital for Sick Children, Toronto, Ontario, Canada; Paula Villaça, MD, Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, São Paulo, Brazil; Jorge Carneiro, MD, Hospital das Clínicas da Faculdade de Medicina USP, São Paulo, Brazil; Margareth Ozelo, MD, Unit of Hemophilia IHTC, Claudio L.P. Correa, Hemocentro Unicamp, INCT do Sangue, University of Campinas, Campinas, Brazil; Sandra Antunes, MD, Universidade Federal de São Paulo, São Paulo, Brazil; Audrey Abad, MSc, The Hospital for Sick Children, Toronto, Ontario, Canada; Brian Feldman, MD, The Hospital for Sick Children, Toronto, Ontario, Canada

(2108) Comparing Communication with Healthcare Providers in Pediatric and Adult Acute Care

Kyle Kemp, University of Calgary, Calgary, Alberta, Canada; Hude Quan, University of Calgary, Calgary, Alberta, Canada; Maria Santana, University of Calgary, Calgary, Alberta, Canada

(2110) Participation of pediatric patients in hospital care, research and intervention development: a systematic review

Lorynn Teela, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Lieke Verhagen, MSc, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Martha Grootenhuis, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Lotte Haverman, PhD, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands

(2112) Measurement Invariance and Agreement of the KIDSCREEN-27 in Children with Mental Disorder and their Parents

Braden Tompke, University of Waterloo, Waterloo, Ontario, Canada; **Mark Ferro, PhD, University of Waterloo, Waterloo, Ontario, Canada**

(2114) HrQoL effects of Growth-Hormone Treatment in Short statured Youth- a controlled prospective study

Monika Bullinger, University Hospital Hamburg Eppendorf, Hamburg, Germany; Janika Bloemeke, Master of Health Sciences, University Hospital Hamburg Eppendorf, Hamburg, Germany; Neuza Silva, Dr., University of Coimbra, Coimbra, Portugal; Julia Quitmann, Dr., University Hospital Hamburg Eppendorf, Hamburg, Germany; Helmuth-Guenther Doerr, University Erlangen- Nuernberg, Erlangen, Germany; submitted on behalf of The German QOLISSY Prospective Group

(2116) A new generic patient-centered instrument to generate health-status values: CS-Base

Paul Krabbe, PhD, University of Groningen, Groningen, Netherlands; Antoinette van Asselt, PhD, University of Groningen, Groningen, Netherlands; Anna Selivanova, PhD, University of Groningen, Groningen, Netherlands; Karin Vermeulen, PhD, University of Groningen, Groningen, Netherlands; Ruslan Jabrayilov, PhD, University of Groningen, Groningen, Netherlands

(2118) Healthcare Utilization, Health-related Quality of Life and Hydroxyurea Adherence in Youth with Sickle Cell Disease

Sherif Badawy, MD, MS, Northwestern University Feinberg School of Medicine - Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, United States; Alexis Thompson, MD, MPH, Northwestern University Feinberg School of Medicine - Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, United States; Jane Holl, MD, MPH, Northwestern University Feinberg School of Medicine - Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, United States; Frank Penedo, PhD, Northwestern University Feinberg School of Medicine, Chicago, IL, United States; Robert Liem, MD, MS, Northwestern University Feinberg School of Medicine - Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, IL, United States

(2120) Predictors of health-related quality of life in chronically ill children and adolescents over time

Ulrike Ravens-Sieberer, Prof. Dr. phil, MPH, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Dana Barthel, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Sandra Nolte, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Ute Thyen, Prof. Dr.med, University of Lübeck, Lübeck, Germany; Marcus Klein, Dr. med., University Medical Center Schleswig-Holstein, Kiel, Germany; Otto Walter, PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Ann-Katrin Meyrose, M.Sc., University Medical Center Hamburg-Eppendorf, Hamburg, Germany; Matthias Rose, Prof. PhD, Charité - Universitätsmedizin Berlin, Berlin, Germany; Christiane Otto, PhD, University Medical Center Hamburg-Eppendorf, Hamburg, Germany

Researcher Health

(2122) Issues in implementing QOL assessment research: An interim report of the qualitative study

Kikuko Miyazaki, PhD, Kyoto University, Kyoto, Japan; Tatsuto Nishigori, MD, PhD, Kyoto University, Kyoto, Japan; Nobuichiro Tamura, MD, Kurashiki Central Hospital, Kurashiki, Japan; Rika Hayashida, RN, MS, University of Nagasaki, Siebold, Nagasaki, Japan; Shinichi Noto, PhD, Niigata University of Health and Welfare, Niigata, Japan; Yoshimi Suzukamo, PhD, Tohoku University, Sendai, Japan

(2124) Pilot study to assess impacts on researchers of conducting emotionally challenging research from consultancy or pharmaceutical settings

Rachel Ballinger, ICON, Abingdon, United Kingdom; Lina Eliasson, Sprout Behaviour Change, London, United Kingdom

Trauma

(2126) Increasing capture of patient-reported outcomes in trauma research

Grace Turner, PhD, University of Birmingham, Birmingham, United Kingdom; Ameeta Retzer, PhD, University of Birmingham, Birmingham, United Kingdom; Anita Slade, PhD, University of Birmingham, Birmingham, United Kingdom; Derek Kyte, PhD, University of Birmingham, Birmingham, United Kingdom; Karen Piper, Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Antonio Belli, MD, FRCS, FRCS (SN), Queen Elizabeth Hospital Birmingham, Birmingham, United Kingdom; Melanie Calvert, PhD, University of Birmingham, Birmingham, United Kingdom

(2128) Prevalence and risk factors for psychological distress after trauma: a prospective cohort study

Leonie de Munter, MSc, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Suzanne Polinder, PhD, Department of Public Health, Erasmus Medical Centre, Rotterdam, Netherlands; Juanita Haagsma, Department of Public Health, Erasmus Medical Centre, Rotterdam, Netherlands; Nena Kruithof, MSc, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Cornelis van de Ree, MD, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Ewout Steyerberg, PhD, Department of Public Health, Erasmus Medical Centre AND Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, Rotterdam, Netherlands; Mariska de Jongh, PhD, Department Trauma TopCare, Elisabeth-TweeSteden Hospital AND Brabant Trauma Registry, Network Emergency Care Brabant, Tilburg, Netherlands

(2130) Post Disaster QOL in a Clinical Sample of Puerto Rican Adolescents

Ligia Chavez, Ph.D., University of Puerto Rico, SAN JUAN, Puerto Rico; Paola Andino Figueroa, MPH, University of Puerto Rico, San Juan, Puerto Rico; Pedro Garcia, MA, University of Puerto Rico, San Juan, Puerto Rico

(2132) Development and Validation of a Psychosocial Screening Instrument for Adult Trauma Patients

Maria Karabatzakis, Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Brenda Den Oudsten, PhD, Center of Research on Psychological and Somatic Disorders (CoRPS), Department of Medical and Clinical Psychology, Tilburg University, Tilburg, Netherlands; Taco Gosens, PhD, Department of Orthopedics and Traumatology, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Jolanda De Vries, PhD, Department of Medical Psychology, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands

(2134) Validation of the World Health Organization Quality of Life Instrument-Short Form (WHOQOL-BREF) for use in the general hospitalized trauma population

Nena Kruithof, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Juanita Haagsma, Erasmus MC University Medical Centre, Department of Public Health, Rotterdam, Netherlands; Maryse Cnossen, Erasmus MC University Medical Centre, Department of Public Health, Rotterdam, Netherlands; Leonie de Munter, ETZ Hospital (Elisabeth-TweeSteden Ziekenhuis), Department Trauma TopCare, Tilburg, Netherlands; Marc van de Ree, ETZ Hospital (Elisabeth-TweeSteden Ziekenhuis), Department Trauma TopCare, Tilburg, Netherlands; Mariska de Jongh, Brabant Trauma Registry, Network Emergency Care Brabant, Tilburg, Netherlands; Suzanne Polinder, Erasmus MC University Medical Centre, Department of Public Health, Rotterdam, Netherlands

(2136) Comparison of the perceived stigmatization measures between general population and Brazilian burned people

Noëlle Freitas, Guarulhos University, Nursing Post-Graduation Program, São Paulo, Brazil; Natássia Pitta, PT, Postgraduate student, University of São Paulo at Ribeirão Preto College of Nursing (Program in Fundamental Nursing), Ribeirão Preto, Brazil; Rosana Dantas, RN, PhD, University of São Paulo at Ribeirão Preto College of Nursing, General and Specialized Nursing Department, Ribeirão Preto, Brazil; Lidia Rossi, RN, PhD, University of São Paulo at Ribeirão Preto College of Nursing, General and Specialized Nursing Department, Ribeirão Preto, Brazil

4:15 pm - 5:45 pm

Concurrent Oral Sessions

Oral Session 205: Psychometrics

Meeting Room 1+2, Second Floor

Session Chair: Skye Barbic, PhD, Canada

4:20 pm – 4:37 pm (205.1) The Factor Structure and Subscale Properties of the Pain Catastrophizing Scale: Are there Differences in the Distinctions?

Karon Cook, PhD, Northwestern University, Houston, TX, United States; Beth Darnall, PhD, Stanford University, Palo Alto, CA, United States; Sean Mackey, MD, PhD, Stanford University, Palo Alto, CA, United States

4:38 pm – 4:55 pm (205.2) Psychometric Evaluation of a New Measure of Quality of Life and Wellness of Health Care Workers in Long Term Care

Oluwagbohunmi Awosoga, PhD, MBA, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Jon Doan, PhD, PEng, Department of Kinesiology & Physical Education, University of Lethbridge, Lethbridge, Alberta, Canada; Claudia Steinke, PhD, Nursing, Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada; Remi Bolarinwa, MSc, Coaldale Health Centre, Alberta Health Services, Lethbridge, Alberta, Canada; Annita Lucchesi, MSc, Faculty of Arts & Science, University of Lethbridge, Lethbridge, Alberta, Canada; Benjamin Dosu, MSc, Faculty of Arts & Science, University of Lethbridge, Lethbridge, Alberta, Canada; Sheli Murphy, PhD, Covenant Health, Edmonton Alberta, Canada; Scott Baerg, MBA, Covenant Health, Edmonton, Alberta, Canada; Oluwaseyi Lawal, MSc, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada; Tolulope Sajobi, PhD, Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

Scientific Program — Friday, 26 October

4:56 pm – 5:13 pm (205.3) The new Health and Self-Management in Diabetes (HASMID-10) measure: Assessing psychometric performance in a large longitudinal survey

Jill Carlton, University of Sheffield, Sheffield, United Kingdom; Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom; Jackie Elliott, PhD, MRCP, University of Sheffield, Sheffield, United Kingdom

5:14 pm – 5:31 pm (205.4) Psychometric Evaluation and Score Interpretation of the Cough Severity Diary (CSD)

Allison Nguyen, Merck & Co., Inc., North Wales, PA, United States; Kim Heithoff, Merck & Co., Inc., Kenilworth, NJ, United States; Elizabeth Bacci, Evidera, Bethesda, MD, United States; Margaret Vernon, Evidera, Bethesda, MD, United States

Oral Session 206: PROs in Clinical Practice

Pembroke & Herbert, Ground Floor

Session Chair: Elizabeth Gibbons, MSc, United Kingdom

4:20 pm – 4:37 pm (206.1) The PACT Study: Acceptability of an integrated model for psychosocial screening, care and treatment of patients with urological and head and neck cancers

Afaf Girgis, Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, UNSW Medicine, The University of New South Wales, Sydney NSW Australia, Sydney, Australia; Hayley Candler, Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, UNSW Medicine, The University of New South Wales, Sydney NSW Australia, Sydney, Australia; Vibeke Hansen, BA Hons (Psych), University Centre for Rural Health, School of Rural Health, University of Sydney, Lismore NSW Australia, Lismore, Australia; Brian Kelly, BMed, PhD, FRANZCP, FACHPM, Priority Research Centre for Translational Neuroscience and Mental Health, Faculty of Health and Medicine, The University of Newcastle; Consultation Liaison Psychiatry Service, Hunter New England Local Health District, John Hunter Hospital, Newcastle NSW, Newcastle, Australia

4:38 pm – 4:55 pm (206.2) Impact of routine assessment of health related quality of life on the satisfaction with care and the health related quality of life of patients with head and neck cancer

Tienhan Sandrine Dabakuyo-Yonli, Epidemiology and Quality of Life Unit, Georges-François Leclerc Cancer Centre-UNICANCER, Dijon, France; Franck Bonnetain, PhD, Methodology and Quality of Life in Oncology Unit (INSERM UMR 1098), University Hospital of Besançon, Besançon, France; Oumar Billa, MD, MSc, Epidemiology and Quality of Life Unit, Georges-François Leclerc Cancer Centre-UNICANCER, Dijon, France; Jérôme Chamois, MD, Centre Hospitalier Saint Grégoire, Saint Gregoire, France; Pierre Truntzer, MD, Paul Strauss Cancer Centre-UNICANCER, Strasbourg, France; Angeline Ligey, MD, Centre Hospitalier FLERIAT, Bourg En Bresse, France; Valérie Ganansia, MD, Paul Strauss Cancer Centre-UNICANCER, Strasbourg, France; Sophie Renard, MD, Institut de Cancérologie de Lorraine, Nancy, France; Sophie Maillard, MD, Centre Bourgogne, Lille, France; Céline Mirjolet, PhD, Radiotherapy Department, Georges-François Leclerc Cancer Centre-UNICANCER, Dijon, France; Gilles Truc, MD, Radiotherapy Department, Georges-François Leclerc Cancer Centre-UNICANCER, Dijon, France; Gilles Crehange, MD, PhD, Radiotherapy Department, Georges-François Leclerc Cancer Centre-UNICANCER, Dijon, France; Philippe Maingon, MD, PhD, Radiotherapy Unit- Hôpital de la Pitié-Salpêtrière - AP-HP, Paris, France

4:56 pm – 5:13 pm (206.3) A Systematic Review of Randomized Controlled Trials Evaluating the Use of Patient Reported Outcome Measures (PROMs)

Sana Ishaque, PhD (candidate), The University of Adelaide, Adelaide, Australia; Jonathan Karnon, The University of Adelaide, Adelaide, Australia; Gang Chen, Monash Business School, Monash University, Adelaide, Australia; Rahul Nair, School of Dentistry, University of Adelaide, Adelaide, Australia; Amy Salter, The University of Adelaide, Adelaide, Australia

5:14 pm – 5:31 pm (206.4) Patient- and family-reported outcome and experience measures across transitions of care for frail seniors living at home: A meta-narrative synthesis

Kara Schick-Makaroff, PhD, MN, BScN, Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada; Mehri Karimi-Dehkordi, PhD, MSc, BSc, University of Ottawa, Edmonton, Alberta, Canada; Sharon Wang, MSN, BSN, Trinity Western University, Langley, British Columbia, Canada; Lena Cuthbertson, BHScOT, Med., PMP, Office of Patient Centred Measurement BC, Ministry of Health, Vancouver, British Columbia, Canada; Richard Sawatzky, PhD, RN, Trinity Western University & Centre for Health Evaluation and Outcome Sciences, Langley, British Columbia, Canada

Oral Session 207: Daily PRO Measurement

Meeting Room 9, Second Floor

Session Chair: Veronique Sebille, ScD, PhD, France

4:20 pm – 4:37 pm (207.1) A qualitative study of patient and clinician perspectives on item importance, scoring preferences, and clinically important differences for two patient-reported outcome measures: Endometriosis Symptom Diary (ESD) and Endometriosis Impact Scale (EIS)

Helen Kitchen, DRG Abacus, Manchester, United Kingdom; Claudia Haberland, Bayer AG, Berlin, Germany; Andrew Trigg, Adelphi Values, Macclesfield, United Kingdom; Natalie Aldhouse, DRG Abacus, Manchester, United Kingdom; Thomas Willgoss, Formerly of DRG Abacus, Manchester, United Kingdom; Heinz Schmitz, Bayer AG, Berlin, Germany; Adam Gater, Adelphi Values, Macclesfield, United Kingdom; Christoph Gerlinger, Bayer AG, Berlin, Germany; Christian Seitz, Bayer AG, Berlin, Germany

4:38 pm – 4:55 pm (207.2) Validation of the “Daily Experience Sampling Questionnaire” (DESQ), an end-of-day diary measuring subjective well-being

Christine Blome, University Medical Center Hamburg, Hamburg, Germany; Natalia Kirsten, MD, University Medical Center Hamburg, Hamburg, Germany; Matthias Augustin, Prof. Dr. med., University Medical Center Hamburg, Hamburg, Germany

Scientific Program — Friday, 26 October

4:56 pm – 5:13 pm (207.3) Psychometric validation of the Endometriosis Symptom Diary (ESD) and Endometriosis Impact Scale (EIS): Findings from an interventional study

Claudia Haberland, Bayer AG, Bollington, United Kingdom; Adam Gater, Adelphi Values Ltd, Bollington, United Kingdom; Dorothea Wessiepe, Metronomia Clinical Research, Munich, Germany; Heinz Schmitz, Bayer AG, Berlin, Germany; Chrisoph Gerlinger, Bayer AG, Berlin, Germany; Christian Seitz, Bayer AG, Berlin, Germany

5:14 pm – 5:31 pm (207.4) Symptom monitoring using patient-reported outcome (PRO) instruments in pediatric oncology patients hospitalized for chemotherapy: A feasibility study

Allison Barz Leahy, Department of Pediatrics, Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Dylan Scholes, Department of Pediatrics, Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Gabrielle Helton, Department of Pediatrics, Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Bryce B. Reeve, PhD, Department of Population Health Sciences, Duke University School of Medicine, Durham, NC, United States; Lisa Schwartz, PhD, Department of Pediatrics, Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Richard Aplenc, MD, PhD, MSCE, Department of Pediatrics, Division of Oncology, Children's Hospital of Philadelphia, Philadelphia, PA, United States; Ethan Basch, MD, MSc, Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill NC, United States

Oral Session 208: Missing Data

Meeting Room 6, Second Floor

Session Chair: Stacie Hudgens, MA, (AbD), United States

4:20 pm – 4:37 pm (208.1) How Much Missing Data is Too Much? Monte Carlo Simulations to Develop SISAQOL Guidelines for Missing Data Handling

Gina L. Mazza, Ph.D., Mayo Clinic, Scottsdale, AZ, United States; Corneel Coens, MSc, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Madeline Pe, PhD, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Lien Dorme, MSc, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Kathy Oliver, BA, International Brain Tumour Alliance, Tadworth, United Kingdom; Andrew Bottomley, PhD, European Organisation for Research and Treatment of Cancer, Brussels, Belgium; Jeff A. Sloan, PhD, Mayo Clinic, Rochester MN, United States; Amylou C. Dueck, PhD, Mayo Clinic, Scottsdale, AZ, United States; submitted on behalf of Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints Data (SISAQOL) Consortium

4:38 pm – 4:55 pm (208.2) Reason for not completing quality of life questionnaires in multiple myeloma patients

Lene Kongsgaard Nielsen, Quality of Life Research Center, Department of Hematology, Odense University Hospital and OPEN, Odense Patient data Explorative Network, Odense University Hospital, Odense, Denmark; Madeleine King, Central Clinical School, Sidney Medical School and Psycho-Oncology Co-operative Research Group, School of Psychology, Sidney, Australia; Mary Jarden, Department of Hematology, Copenhagen University Hospital, Copenhagen, Denmark; Christen Lykkegaard Andersen, Department of Hematology, Zealand University Hospital, Roskilde, Denmark; Henrik Frederiksen, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark; Henrik Gregersen, Department of Hematology, Aalborg University Hospital, Aalborg, Denmark; Anja Klostergaard, Department of Hematology, Aarhus University Hospital, Aarhus, Denmark; Morten Saaby Steffensen, Department of Hematology, Regional Hospital West Jutland, Holstebro, Denmark; Per Trøllund Pedersen, Department of Hematology, South West Jutland Hospital, Esbjerg, Denmark; Bettina Broch, Department of Hematology, Vejle Hospital, Vejle, Denmark; Mikael Frederiksen, Department of Hematology, Hospital of Southern Jutland, Aabenraa, Denmark; Bo Amdi Jensen, Department of Hematology, Zealand University Hospital, Roskilde, Denmark; Carsten Helleberg, Department of Hematology, Herlev Hospital, Herlev, Denmark; Anne Kærgaard Mylin, Department of Hematology, Copenhagen University Hospital, Copenhagen, Denmark; Niels Abildgaard, Quality of Life Research Center, Department of Hematology, Odense University Hospital, Odense, Denmark

STUDENT ORAL PRESENTATION AWARD FINALIST

4:56 pm – 5:13 pm (208.3) Differential PRO completion rates between arms in open-label cancer trials: Can principal stratification help?

Jessica Roydhouse, PhD, US Food and Drug Administration, Silver Spring, MD, United States; Pallavi Mishra-Kalyani, PhD, US Food and Drug Administration, Silver Spring, MD, United States; Vishal Bhatnagar, MD, US Food and Drug Administration, Silver Spring, MD, United States; Roeel Gutman, PhD, Brown University School of Public Health, Providence, RI, United States; Bellinda King-Kallimanis, PhD, US Food and Drug Administration, Silver Spring, MD, United States; Paul Kluetz, MD, US Food and Drug Administration, Silver Spring, MD, United States

5:14 pm – 5:31 pm (208.4) Handling informative drop-out in longitudinal analysis of health-related quality of life: Application on data from the oesophageal cancer clinical trial PRODIGES/ACCORD17

Benjamin Cuet, PhD Student, Montpellier Cancer Institute (ICM) – Val d'Aurelle, Univ Montpellier, Montpellier, France; Caroline Mollevi, Montpellier Cancer Institute (ICM) – Val d'Aurelle, Univ Montpellier, IRCM, Univ Montpellier, ICM, INSERM, French National Platform Quality of Life and Cancer, Montpellier, France; Amélie Anota, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, French National Platform Quality of Life and Cancer, Besançon, France; Emilie Charton, PhD Student, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, Besançon, France; Franck Bonnetain, Methodology and Quality of Life Unit in Oncology, INSERM UMR 1098, University Hospital of Besançon, French National Platform Quality of Life and Cancer, Besançon, France; Thierry Conroy, Institut de Cancérologie de Lorraine (ICL), Vandoeuvre-lès-Nancy, France; Beata Juzyna, R&D Unicancer, Paris, France; Sophie Gourgou, Montpellier Cancer Institute (ICM) – Val d'Aurelle, Univ Montpellier, Montpellier, France; Célia Touraine, Montpellier Cancer Institute (ICM) – Val d'Aurelle, Univ Montpellier, Montpellier, France

6:15 pm Dine Arounds

Meet in Lobby

Social event with pre-registration required

Scientific Program — Saturday, 27 October

7:00 am - 5:20 pm	Registration Desk Open	Pre-Function Area, Ground Floor
8:00 am - 8:30 am	President's Address	Pembroke & Herbert, Ground Floor
8:30 am - 9:45 am	ISOQOL Member Business Meeting	Pembroke & Herbert, Ground Floor
9:45 am - 10:15 am	Refreshment Break	Fitzwilliam Suites, Ground Floor
9:45 am - 10:15 am	Saturday Poster Session I	Lansdowne Room, Ground Floor

Diabetes

(3003) Content validity of disease-specific Health-Related Quality of Life instruments for patients with type 2 diabetes mellitus

Cecilia AC Prinsen, Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam Public Health research institute, Amsterdam, Netherlands; Amber A van der Heijden, Department of General Practice and Elderly Care, VU University Medical Center, Amsterdam Public Health research institute, Amsterdam, Netherlands; Femke Rutters, Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam Public Health research institute, Amsterdam, Netherlands; Geetha Mukerji, Women's College Hospital, Toronto, Ontario, Canada; Ilana Halperin, Division of Endocrinology, Department of Medicine, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, Ontario, Canada; Maartje de Wit, Department of Medical Psychology, VU University Medical Center, Amsterdam, Netherlands; Petra Elders, Department of General Practice and Elderly Care, VU University Medical Center, Amsterdam Public Health research institute, Amsterdam, Netherlands; Joline WJ Beulens, Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam Public Health research institute, Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Amsterdam, Utrecht, Netherlands; **Caroline B Terwee, Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam Public Health research institute, Amsterdam, Netherlands**

(3005) Individualised, condition-specific measures of quality of life, designed using a common template and item bank, facilitate cross-condition comparisons.

Clare Bradley, Health Psychology Research Unit, Royal Holloway, University of London, London, United Kingdom; Jacquelyn Romaine, PhD, Health Psychology Research Unit, Royal Holloway, University of London, London, United Kingdom; Andrea Gibbons, PhD, Health Psychology Research Unit, Royal Holloway, University of London, London, United Kingdom

(3007) The American Neurogastroenterology and Motility Society Gastroparesis Cardinal Symptom Index-Daily Diary (ANMS GCSI-DD): Assessing Qualitative Validity and Electronic Usability in Patients with Idiopathic or Diabetic Gastroparesis

Dennis Revicki, Evidera, Bethesda, MD, United States; Sara Gleeson, MPH, Evidera, Bethesda, MD, United States; **Rebecca Speck, PhD, Evidera, Bethesda, MD, United States;** Jorge Puelles, PharmD, MSc, MBA, Takeda Pharmaceuticals, London, United Kingdom; Braden Kuo, MD, Massachusetts General Hospital, Boston, MA, United States; Michael Camilleri, MD, Mayo Clinic, Rochester, MN, United States; Henry Parkman, MD, Temple University Hospital, Philadelphia, PA, United States

(3009) PROM validation using paper-based or online surveys: Data collection methods affect the sociodemographic and health profile of the sample

Donna Rowen, University of Sheffield, Sheffield, United Kingdom; Jill Carlton, PhD, University of Sheffield, Sheffield, United Kingdom; Jackie Elliot, PhD, MRCP, University of Sheffield, Sheffield, United Kingdom

(3011) Chronic Fatigue is associated with a significant reduction of Health-Related Quality of life (HRQoL) in type 1 diabetes.

Øystein Jensen, Ph.d student, Østfold University College, Halden, Norway; Tomm Bernklev, Professor, Vestfold Hospital Trust, Tønsberg, Norway; Charlotte Gibbs, Medical Doctor, Telemark Hospital Trust, Skien, Norway; Ragnar Bekkhus-Moe, Medical Doctor, Østfold Hospital Trust, Moss, Norway; Dag Hofsvø, Medical Doctor, Vestfold Hospital Trust, Tønsberg, Norway; Lars-Petter Jelsness-Jørgensen, Professor, Østfold University College, Halden, Norway

Drug Users

(3013) Quality of Life of Marijuana Users and Factors Associated with Marijuana Use: The Arkansas Marijuana Study
Nalin Payakachat, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States; Lauren Russell, BSc, University of Arkansas for Medical Sciences, Little Rock, AR, United States; William Fantegrossi, PhD, University of Arkansas for Medical Sciences, Little Rock, AR, United States

(3015) Anxiety disorders, mood disorders, psychiatric symptoms and quality of life of drug users in outpatient treatment in Brazil

Selva Campêlo, Master, Federal University of Goiás, Goiânia, Brazil; Maria Barbosa, PhD, Federal University of Goiás, Goiânia, Brazil; Danilo Dias, PhD, Federal University of Goiás, Goiânia, Brazil

E-Health Development

(3017) Thrive – A Human-Centered Universal PRO System for Self-Management, Digital Discovery, and Personalized Medicine

Emil Chiauzzi, PatientsLikeMe, Cambridge, MA, United States; Paul Wicks, PhD, PatientsLikeMe, Cambridge, MA, United States; Stacey McCaffrey, PhD, PatientsLikeMe, Cambridge, MA, United States; Kim Goodwin, PatientsLikeMe, Cambridge, MA, United States; Ryan Black, PhD, PatientsLikeMe, Cambridge, MA, United States; Michael Hoole, PatientsLikeMe, Cambridge, MA, United States; James Heywood, PatientsLikeMe, Cambridge, MA, United States

(3019) Development of A Web Database Platform for Multidimensional Dynamic Assessing of Quality of Life

Zhongyu Huang, Guangzhou University of Chinese Medicine, Canton, China; **Fengbin Liu, MD, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China;** Zhengkun Hou, MD, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China; Yuefeng Wu, MSc, The First Affiliated Hospital of Guangzhou University of Chinese Medicine, Canton, China

(3021) Designing a user-friendly web-interface with prediction models for survival, health-related quality-of-life and toxicity for cancer patients

Héctor van den Boorn, Department of Medical Oncology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Loïs van de Water, Department of Medical Oncology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Florian Hoxha, Department of Medical Informatics, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Inge Henselmans, Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Jessy Joy van Kleef, Department of Medical Oncology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Mirjam Sprangers, Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Martijn van Oijen, Department of Medical Oncology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Ameen Abu-Hanna, Department of Medical Informatics, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Koos Zwinderman, Department of Clinical Epidemiology, Biostatistics and Bioinformatics, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Ellen Smets, Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands; Hanneke van Laarhoven, Department of Medical Oncology, Academic Medical Center, University of Amsterdam, Amsterdam, Netherlands

(3023) Implementing and Integrating Patient Reported Outcomes Data Capture in an Academic Medical Center Setting

Jason Guattery, Washington University School of Medicine, St. Louis, MO, United States; Amanda Spraggs-Hughes, MA, Washington University School of Medicine, St. Louis, MO, United States; Ryan Calfee, MD, MSc, Washington University School of Medicine, St. Louis, MO, United States

(3025) Can wearables and sensor data be used to add context to activities of daily living questionnaires?

Marie Mc Carthy, ICON Plc, Dublin, Ireland; Darragh Walsh, BSc, ICON Plc, Dublin, Ireland; Jamie Tallon, ICON PLC, Dublin, Ireland; Willie Muehlhausen, DVM, ICON PLC, Dublin, Ireland

(3027) Withdrawn

HIV

(3029) Differences on quality of life between HIV-infected adults since childhood and non-HIV infected persons

Adrian Luca, Lecturer Phd, University of Bucharest, Bucharest, Romania; **Anca Luca, Clinical Psychologist, Dr. Victor Babeş Hospital for Infectious and Tropical Diseases, Bucharest, Romania;** Florin Lazar, Professor Phd, Faculty of Sociology and Social Work, University of Bucharest, Bucharest, Romania; Luminita Ene, Medical Scientist Phd, Dr. Victor Babeş Hospital for Infectious and Tropical Diseases, Bucharest, Romania; Roxana Radoi, Medical Scientist, Dr. Victor Babeş Hospital for Infectious and Tropical Diseases, Bucharest, Romania; Adina Talnariu, Clinical Psychologist, Dr. Victor Babeş Hospital for Infectious and Tropical Diseases, Bucharest, Romania; Silvia Suci, Social Worker, Dr. Victor Babeş Hospital for Infectious and Tropical Diseases, Bucharest, Romania; Cristian Achim, Professor Phd., University of California San Diego, La Jolla, San Diego, CA, United States

(3031) Confirming the psychometric properties of the 16-Item Well-Being Questionnaire (W-BQ16) with people living with HIV in the UK and the US.

Jacquelyn Romaine, PhD, Health Psychology Research Unit, Royal Holloway, University of London, London, United Kingdom; Miranda Murray, PhD, ViiV Healthcare Ltd, London, United Kingdom; Clare Bradley, PhD, Health Psychology Research Unit, Royal Holloway, University of London, London, United Kingdom

(3033) The Loneliness of Living with HIV

Nancy Mayo, BSc(PT), MSc, PhD, McGill University, Montreal, Quebec, Canada; Marie-Josée Brouillette, MD, FRCP, McGill University, Montreal, Quebec, Canada; Lesley Fellows, MDCM, PhD, FRCP, McGill University, Montreal, Quebec, Canada; Marianne Harris, MD, University of British Columbia, Vancouver, British Columbia, Canada

Methods for Understanding Meaningful Change and Clinical Importance

(3035) Interpreting changes in scores: the case of the Recovering Quality of Life (ReQoL)

Anju Keetharuth, University of Sheffield, Sheffield, United Kingdom; Micheal Barkham, PhD, University of Sheffield, Sheffield, United Kingdom; John Brazier, PhD, University of Sheffield, Sheffield, United Kingdom

(3037) The quality in reporting of studies determining the Minimal Clinically Important Difference of a Patient-Reported Outcomes: a systematic review and a first proposal of guidelines.

Antoine Vanier, MD, PhD, Inserm U1246 SPHERE - University of Nantes, Nantes, France; Véronique Sébille, PhD, ScD, Inserm U1246 SPHERE - University of Nantes, Nantes, France; Alexandra Rouquette, MD, PhD, Inserm CESP - University of Paris-Sud 11, Le Kremlin-Bicêtre, France; Jean-Benoit Hardouin, PhD, ScD, Inserm U1246 SPHERE - University of Nantes, Nantes, France

(3039) Qualitative methods for exploring meaningful change thresholds, including the use of vignettes: value, implementation and learnings

Laura Grant, Adelphi Values Ltd, Bollington, United Kingdom; Claire Trennery, Adelphi Values Ltd, Bollington, United Kingdom; Lotte Seiding Larsen, Leo Pharma A/S, Ballerup, Denmark; Rob Arbuckle, Adelphi Values Ltd, Bollington, United Kingdom

(3041) Developing a New Module of the BREAST-Q to Measure Outcomes for Patients with Lymphedema: A Qualitative Study

Elena Tsangaris, Harvard University, Boston, MA, United States; Anne Klassen, McMaster University, Hamilton, Ontario, Canada; Manraj Kaur, McMaster University, Hamilton, Ontario, Canada; Linda Vriend, Erasmus Medical Center, Rotterdam, Netherlands; Dalibor Vasilic, Erasmus Medical Center, Rotterdam, Netherlands; Andrea Pusic, Harvard Medical School, Boston, MA, United States

(3043) Development of thresholds for clinical importance for the EORTC QLQ-C30 and the computer-adaptive EORTC measures

Fanny L Loth, MSc, Medical University of Innsbruck, Innsbruck, Austria; Bernhard Holzner, Medical University of Innsbruck, Innsbruck, Austria; Neil K Aaronson, The Netherlands Cancer Institute, Amsterdam, Netherlands; Juan I Arraras, Hospital of Navarre, Pamplona, Spain; Fabio Efficace, Italian Group for Adult Hematologic Diseases (GIMEMA) Data Center, Rome, Italy; John Ramage, Hampshire Hospitals NHS Foundation Trust, Basingstoke, United Kingdom; Mogens Groenvold, University of Copenhagen, Copenhagen, Denmark; Jacobien M Kieffer, The Netherlands Cancer Institute, Amsterdam, Netherlands; Morten Aa Petersen, University of Copenhagen, Copenhagen, Denmark; Krzysztof Tomaszewski, Ignatianum Academy, Krakow, Poland; Teresa Young, Mount Vernon Cancer Centre, Northwood, United Kingdom; Johannes M Giesinger, Medical University of Innsbruck, Innsbruck, Austria

(3045) 2MCID: A novel approach to strengthening the utility of the concept of MCID

Faraz Ali, MBChB, Department of Dermatology and Wound Healing, Division of Infection and Immunity, School of Medicine, College of Biomedical and Life Sciences, Cardiff University, Cardiff, United Kingdom; Andrew Y Finlay, Department of Dermatology and Wound Healing, Division of Infection and Immunity, School of Medicine, College of Biomedical and Life Sciences, Cardiff University, Cardiff, United Kingdom; Sam Salek, School of Life and Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom

(3047) Reference Values for EORTC QLQ-C30 in Early and Metastatic Breast Cancer

Justyna Mierzynska, European Organisation of Research and Treatment for Cancer, Quality of Life department, Brussels, Belgium; Madeline Pe, European Organisation of Research and Treatment for Cancer, Quality of Life department, Brussels, Belgium; Corneel Coens, European Organisation of Research and Treatment for Cancer, Quality of Life department, Brussels, Belgium; Francesca Martinelli, European Organisation of Research and Treatment for Cancer, Quality of Life department, Brussels, Belgium; Katarzyna Pogoda, Department of Breast Cancer and Reconstructive Surgery, Maria Sklodowska-Curie Institute – Oncology Center, Warsaw, Poland; Galina Velikova, Leeds Institute of Cancer and Pathology, University of Leeds, Leeds, United Kingdom; Vesna Bjelic-Radicic, Department of Gynecology and Obstetrics, Medical University of Graz, Graz, Austria; Fatima Cardoso, Breast Unit, Champalimaud Clinical Center-Champalimaud Foundation, Lisbon, Portugal; Etienne Brain, Department of Medical Oncology, Institut Curie, Paris & Saint Cloud, France; Michail Ignatiadis, Department of Medical Oncology, Jules Bordet Institute, Brussels, Belgium; Martine Piccart, Department of Medical Oncology, Jules Bordet Institute, Brussels, Belgium; Emiel Rutgers, Department of Surgical Oncology, Netherlands Cancer Institute, Amsterdam, Netherlands; Geertjan Van Tienhoven, Department of Radiation Oncology, Academic Medical Centre, Amsterdam, Netherlands; Robert Mansel, Department of Surgery, Cardiff University, Cardiff, United Kingdom; Hans Wildiers, Department of General Medical Oncology, University Hospitals Leuven, Leuven, Belgium; Andrew Bottomley, European Organization of Research and Treatment for Cancer, Quality of Life department, Brussels, Belgium; submitted on behalf of EORTC and EORTC Breast Cancer Group

(3049) Identification of MCIDs for foot and ankle patients

Man Hung, PhD, University of Utah, Salt Lake City, UT, United States; Judith Baumhauer, MD, University of Rochester Medical Center, Rochester, NY, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Maren Voss, ScD, University of Utah, Salt Lake City, UT, United States; Julie Xu, BS, University of Utah, Salt Lake City, UT, United States; Shirley Hon, BS, University of Utah, Salt Lake City, UT, United States; Charles Saltzman, MD, University of Utah, Salt Lake City, UT, United States

(3051) Evaluation of responsiveness and estimation of minimal clinically important difference (MCID) scores for the Childhood Atopic Dermatitis Impact Scale

Michaela Gabes, Medical Sociology, University of Regensburg, Regensburg, Germany; Sarah L. Chamlin, M.D., Ann and Robert H. Lurie Children's Hospital of Chicago and Northwestern Feinberg School of Medicine, Chicago, IL, United States; Jin-Shei Lai, PhD, OTR, Department of Medical Social Sciences Feinberg School of Medicine, Northwestern University, Chicago, IL, United States; David Cella, PhD, Department of Medical Social Sciences Feinberg School of Medicine, Northwestern University, Chicago, IL, United States; Anthony J. Mancini, M.D., Ann and Robert H. Lurie Children's Hospital of Chicago and Northwestern Feinberg School of Medicine, Chicago, IL, United States; Christian Apfelbacher, PhD, Medical Sociology, University of Regensburg, Regensburg, Germany

(3053) Investigation of the minimally important difference of HRQOL in stroke patients on recovery-phase rehabilitation wards -Using anchor-based and distribution-based methods-

Ryota Izumi, PhD, Seirei Christopher University, Hamamatsu, Japan; Tetsuya Sano, Suzukake Healthcare Hospital, Iwata, Japan; Hirokazu Takizawa, Todachuo Rehabilitation Hospital, Toda, Japan; Yasuhiro Yamamoto, Kanazawa Neurosurgical Hospital, Kanazawa, Japan; Asami Hori, Niigata Rehabilitation Hospital, Niigata, Japan; Akane Wada, Hamamatsu City Rehabilitation Hospital, Hamamatsu, Japan; Eiko Iguchi, Juzen Memorial Hospital, Hamamatsu, Japan; Yoshimi Suzukamo, Tohoku University, Sendai, Japan; Shin-ichi Noto, Niigata University of Health and Welfare, Niigata, Japan

(3055) Minimally important difference and responsiveness of the MD Anderson Symptom Inventory in evaluating symptom severity and interference in cancer patients

Tito Mendoza, University of Texas MD Anderson Cancer Center, Houston, TX, United States; David Eton, Mayo Clinic, Rochester, MN, United States; Kathleen Yost, Mayo Clinic, Rochester, MN, United States; Paul Novotny, Mayo Clinic, Rochester, MN, United States; Amylou Dueck, Mayo Clinic, Scottsdale, AZ, United States; Timothy Beebe, University of Minnesota, Minneapolis, MN, United States; Marlene Frost, Mayo Clinic, Minneapolis, MN, United States; Loretta Williams, University of Texas MD Anderson Cancer Center, Houston, TX, United States; Charles Cleeland, The University of Texas MD Anderson Cancer Center, Houston, TX, United States; Jeff Sloan, Mayo Clinic, Rochester, MN, United States

Patient Engagement

(3057) Leveraging Patient Engagement to Develop a Disease-Specific Patient-Reported Outcome Measure

Allison Nguyen, Merck & Co., Inc., North Wales, PA, United States; Valerie Powell, Mapi Group an ICON plc Company, Boston, MA, United States; Kelly Franchetti, Mapi Group an ICON plc Company, Boston, MA, United States; Yanfen Guan, Merck & Co., Inc., Kenilworth, NJ, United States; Mary Elmer, Merck & Co., Inc., Kenilworth, NJ, United States; Luther Clark, Merck & Co., Inc., Kenilworth, NJ, United States; Felipe Arbelaez Casas, Merck & Co., Inc., Kenilworth, NJ, United States

(3059) The use of patient perspectives to develop and pretest a scale of meaningful patient engagement in health research projects

Clayton Hamilton, PhD, Department of Physical Therapy, University of British Columbia, Vancouver, British Columbia, Canada; Alison Hoens, MSc, BC SUPPORT Unit, Vancouver, British Columbia, Canada; Shanon McQuitty, Arthritis Patient Advisory Board - Arthritis Research Canada, Richmond, British Columbia, Canada; Annette McKinnon, Arthritis Patient Advisory Board - Arthritis Research Canada, Richmond, British Columbia, Canada; Kelly English, Arthritis Patient Advisory Board - Arthritis Research Canada, Richmond, British Columbia, Canada; Catherine Backman, PhD, Department of Occupational Science & Occupational Therapy, University of British Columbia, Vancouver, British Columbia, Canada; Negar Khodarahmi, BA, Arthritis Research Canada, Richmond, British Columbia, Canada; Tara Azimi, MA, Arthritis Research Canada, Richmond, British Columbia, Canada; Linda Li, PhD, Department of Physical Therapy, University of British Columbia, Vancouver, British Columbia, Canada

(3061) Obtaining Patient Priorities in Delivering Patient Centered Care: Beyond Patient Reported Outcomes

Deborah Miller, PhD, LISW-S, Cleveland Clinic Mellen Center, Cleveland, OH, United States; Brandon Moss, MD, Mellen Center, Cleveland Clinic, Cleveland, OH, United States; Susannah Rose, PhD, Office of Patient Experience, Cleveland Clinic, Cleveland, OH, United States; Malory Weber, MBA, Mellen Center, Cleveland Clinic, Cleveland, OH, United States; David Schindler, BS, Biomedical Engineering, Cleveland, OH, United States; Hong Li, MS, Quantitative Health Sciences, Cleveland Clinic, Cleveland, OH, United States; Sarah Planchon, PhD, Mellen Center, Cleveland Clinic, Cleveland, OH, United States; Robert Bermel, MD, Mellen Center, Cleveland Clinic, Cleveland, OH, United States

(3063) Why do patient research partners and researchers engage in a long-term co-creative collaboration?

Louise Aaro, Patient research partner, Linköping, Sweden; Lars E. Eriksson, RN, MSc, PhD, Karolinska Institutet, Stockholm, Sweden; David Hill, Patient research partner, Gothenburg, Sweden; Claudia Lampic, PhD, Karolinska Institutet, Stockholm, Sweden; Åsa Månsson D'Souza, Patient research partner, Bromma, Sweden; Johanna Sörensen, Patient research partner, Stockholm, Sweden; Carolin Viklund, Patient research partner, Stockholm, Sweden; **Lena Wettergren, RN, PhD, Karolinska Institutet, Stockholm, Sweden**

(3065) The development of a game to facilitate pediatric patient participation in hospital care, research and intervention development

Lorynn Teela, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Lieke Verhagen, MSc, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands; Martha Grootenhuis, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, Netherlands; Lotte Haverman, PhD, Psychosocial Department Emma Children's Hospital Amsterdam UMC, Amsterdam, Netherlands

(3067) A Patient Engagement Method Overview: Examples of Valuing Patient Voice in Psychology, Disease Conditions and Mental Health Using Group Concept Mapping

Mary Kane, MSLIS, Concept Systems, Inc., Ithaca, NY, United States

(3069) Shared decision-making in spine surgery: Pilot study of the use of patient reported outcomes to improve decision-making

Richard Skolasky, Johns Hopkins University, Baltimore, United States; Brian Neuman, M.D., Johns Hopkins University, Baltimore, MD, United States

Rare Conditions

(3073) Identifying relevant and important quality of life (QoL) issues for people with primary sclerosing cholangitis (PSC) through group discussions and interviews

Elena Marcus, University College London, London, United Kingdom; Douglas Thorburn, MB ChB, Royal Free London NHS Foundation Trust, London, United Kingdom; Patrick Stone, MB ChB, University College London, London, United Kingdom; Bella Vivat, MSc PhD, University College London, London, United Kingdom

(3075) Quality of life in adults with a rare diagnosis

Jintana B. Andersen, Centre for Rare Disorders, Oslo University Hospital, Oslo, Norway, Oslo, Norway; Kristin J. B. Feragen, PhD, Centre for Rare Disorders, Oslo University Hospital, Oslo, Norway, Oslo, Norway

(3077) Quality of life in Duchenne muscular dystrophy (DMD): initial findings and protocol for a new preference-based measure

Philip Powell, PhD, University of Sheffield, Sheffield, United Kingdom; Jill Carlton, PhD, University of Sheffield, Sheffield, United Kingdom; Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom; Lesley Uttley, PhD, University of Sheffield, Sheffield, United Kingdom; Helen Buckley-Woods, MSc, University of Sheffield, Sheffield, United Kingdom; John Brazier, PhD, University of Sheffield, Sheffield, United Kingdom

Student Health

(3079) Health Behaviours, Self-efficacy and Quality of Life of Clinical and Non-clinical Students at a tertiary Institution in Nigeria

Adesola Odole, College of Medicine, University of Ibadan, Ibadan, Nigeria; Sandra Charles, College of Medicine, University of Ibadan, Ibadan, Nigeria; Nse Odunaiya, College of Medicine, University of Ibadan, Ibadan, Nigeria

(3081) Mental health in university students

Ana Gabriela Magallanes Rodríguez, PhD, Universidad Autonoma de Baja California, Tijuana, Mexico; Luis Horacio Aguiar Palacios, Master, Universidad Autonoma de Baja California, Tijuana, Mexico; Julio Roman Martinez Alvarado, PhD, Universidad Autonoma de Baja California, Tijuana, Mexico; Karina Rodriguez Fuentes, Master, Universidad Autonoma de Baja California, Tijuana, Mexico

(3083) Quality of life and marijuana-related behaviors among university students from Valparaiso, Chile

Carlos Alejandro Hidalgo-Rasmussen, Centro de Investigacion en Riesgos y Calidad de Vida (CIRCAV), University of Guadalajara, Mexico/ Centro de Estudios Avanzados (CEA), University of Playa Ancha, Chile, Cd. Guzman, Mexico; Maria Jacqueline Rojas, PhD, Facultad de Ciencias de la Educacin, University of Playa Ancha, Viña del Mar, Chile; Fabiola Vilugron-Aravena, MD, Facultad de Ciencias de la Salud, Universidad de Playa Ancha, Valparaiso, Chile; Karina Franco-Paredes, PhD, Departamento de Promocin, preservacin y desarrollo de la Salud, Centro de Investigacin en Riesgos y Calidad de Vida (CIRCAV). University of Guadalajara, Cd. Guzman, Mexico; Felipe de Jesus Diaz-Resendiz, PhD, Departamento de Promocin, preservacin y desarrollo de la Salud, Centro de Investigacin en Riesgos y Calidad de Vida (CIRCAV). University of Guadalajara, Cd. Guzmán, Mexico; Veronica Pasten, PhD, Facultad de Ciencias de la Educacin, Universidad de Playa Ancha, Valparaiso, Chile; Kathia Anahi Zurita-Aguilar, MD, Doctorado en Psicologa con orientacin en calidad de vida y Salud/ University of Guadalajara, Cd. Guzman, Mexico; Yolanda Viridiana Chavez-Flores, PhD, Centro de Investigacion en Riesgos y Calidad de Vida/ University of Guadalajara, Cd. Guzman, Mexico; Yolanda Viridiana Chavez-Flores, PhD, Centro de Investigacion en Riesgos y Calidad de Vida/University of Guadalajara, Tijuana, Mexico; Libia Yanelli Yanez-Penunuri, PhD, University of Sonora, Sonora, Mexico

(3085) Quality of life and tobacco consumption among young Chilean students, by gender

Carlos Alejandro Hidalgo-Rasmussen, Centro de Investigacion en Riesgos y Calidad de Vida (CIRCAV), University of Guadalajara, Mexico/ Centro de Estudios Avanzados (CEA), University of Playa Ancha, Chile, Cd. Guzman, Mexico; Maria Jacqueline Rojas, PhD, Facultad de Ciencias de la Educación, University of Playa Ancha, Viña del Mar, Chile; Fabiola Vilugron-Aravena, MD, Facultad de Ciencias de la Salud, University of Playa Ancha, Valparaiso, Chile; Karina Franco-Paredes, PhD, Departamento de Promoción, Preservación y desarrollo de la Salud, Centro de Investigacin en Riesgos y Calidad de Vida (CIRCAV), University of Guadalajara, Cd. Guzman, Mexico; Felipe Diaz-Resendiz, PhD, Departamento de Promoción, Preservación y desarrollo de la Salud, Centro de Investigación en Riesgos y Calidad de Vida (CIRCAV), University of Guadalajara, Cd. Guzman, Mexico; Yolanda Viridiana Chavez-Flores, PhD, Centro de Investigacion en Riesgos y Calidad de Vida (CIRCAV)/University of Guadalajara, Tijuana, Mexico; Libia Yanelli Yanez-Penunuri, PhD, Universidad de Sonora, Hermosillo, Mexico; Kathia Anahi Zurita-Aguilar, MD, Doctorado en Psicología con orientacin en calidad de vida y salud/ University of Guadalajara, Cd. Guzman, Mexico; Sandra Paola Javier-Juarez, Psic., Maestría en Psicología con orientacin en calidad de vida y salud, University of Guadalajara, Cd. Guzman, Mexico; Veronica Pasten, PhD, Facultad de Ciencias de la Educación, University of Playa Ancha, Valparaiso, Chile

(3089) Health-Related Quality of Life and Health Risk Behaviors among Saudi University Students Studying Health Sciences

Hanaa Al Anazi, MPH, Saudi Health Council, Riyadh, Saudi Arabia; Ashraf al metwally, PhD, KSAU-HS, Riyadh, Saudi Arabia

(3091) Withdrawn

Scientific Program — Saturday, 27 October

(3093) Impaired quality of life of undergraduate and postgraduate medical students. Results from the national BOURBON study.

Guillaume Fond, MD PHD, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France; **Mohamed Boucekine, MsC, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France**; Aliénor Bourbon, MD, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France; Christophe Lancon, MD PhD, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France; Pascal Auquier, Md PhD, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France; Laurent Boyer, MD PhD, Aix-Marseille Univ, Faculté de Médecine - Secteur Timone, EA 3279: CEReSS -Centre d'Etude et de Recherche sur les Services de Santé et la Qualité de vie, Marseille, France

10:15 am - 11:00 am Awards Presentation & 2019 Conference Announcement **Pembroke & Herbert, Ground Floor**

The following awards will be announced at the Awards Presentation:

2018 President's Award
Outstanding Articles of the Year (QLR and JPRO)
New Investigator and Student Presentation Awards
Outstanding Poster Award
Emerging Leader Award
Travel Scholarships

11:00 am - 12:30 pm Plenary: Generalizability of validity data across diseases and treatment settings: when is enough, enough? **Pembroke & Herbert, Ground Floor**

Sponsored by: Roche



The past two years have seen a trend toward recognizing that a given HRQoL questionnaire that measures a common and reasonably well-defined concept can be regarded as valid, and even "fit for purpose," if it has been tested and proven valid in many settings and diseases, but not necessarily the proposed new disease. In this plenary, we consider what the use of PROs in the digital age means for the concept of validity and how we apply PROs in drug development and trials.

Chair:

Madeleine King, BSc (Hons), DipMedStat, PhD, University of Sydney, Sydney, Australia

Speakers:

Laura Lee Johnson, PhD, U.S. Food and Drug Administration, Silver Spring, MD, United States

David Cella, PhD, Northwestern University, Chicago, IL, United States

Stefan Cano, PhD, CPsychol, AFBPsS, Modus Outcomes, Letchworth Garden City, United Kingdom

Leah McClimans, PhD, University of South Carolina, Columbia, SC, United States

12:30 pm - 2:00 pm Buffet Lunch Break **Sussex Restaurant, Ground Floor**

12:30 pm - 1:15 pm First Lunch Shift
1:15 pm - 2:00 pm Second Lunch Shift

The conference registration fee includes a buffet lunch served in the Sussex Restaurant on the Ground Floor. Two lunch shifts are scheduled each day to help attendees maximize break times to include other scheduled meetings in the conference program. Entry into the restaurant is by name badge.

12:35 pm - 1:30 pm Special Interest Group (SIG) Meetings

Ibero America SIG **Meeting Room 5**
New Investigator SIG **Meeting Room 9**
QOL in Clinical Practice SIG **Pembroke & Herbert**
Response Shift SIG **Meeting Room 1+2**
Translation and Cultural Adaptation SIG **Meeting Room 6**

Scientific Program — Saturday, 27 October

2:00 pm - 3:15 pm Concurrent Symposium Sessions

Symposium 5: What Matters to You: Measuring Patient Experiences Pembroke & Herbert, Ground Floor



Sponsored by: Incyte

Moderator:

Elizabeth Gibbons, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

Patient-reported experience measures (PREMs) are patient reports and ratings of aspects of care such as access to care, provider communication, involvement in decision-making, care coordination, and staff courtesy and respect. PREMs yield information about the extent to which care is responsive to patient needs, values and preferences. PREMs were developed to support evaluation of the quality of health care received and have been used to monitor improvement in health care services.

The overall objective of this symposium is to describe the assessment of patient experiences in different countries. We will present new initiatives (person-centered indicators) and techniques (using machine learning and natural language processing) for assessing patient experience, and we will discuss programs that may allow the standardization of these assessments and improve the understanding of what they mean and in what circumstances the integration of PREMs data into big data leads to improvements in patient care.

The symposium will include presentations on: 1) methods of measuring patient experiences and the role of PREMs; 2) how patient experience is assessed in England, USA and Canada; 3) evidence-based and patient/caregiver/community informed indicators; and 4) using automated systems to make sense of open-text comments in order to supplement PREMs and to gain actionable insights into healthcare quality and improvement.

Individual Presenters:

The Role of Patient-reported outcomes in Health Care Quality Improvement in Canada

Maria J. Santana, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

The evolution of the measurement of patient experience in England

Jenny King, Picker Institute Europe, Oxford, United Kingdom

Not just a tick-box exercise: realizing the value of written patient comments using machine learning and natural language processing

Chris Gibbons, Brigham and Women's Hospital / Harvard Medical School, Boston, MA, United States

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Approach to Assessing Patient Experiences with Care in the United States

Ronald Hays, PhD, UCLA School of Medicine, Los Angeles, CA, United States

Symposium 6: A PRO-cision Medicine Toolkit: Methods for Aiding Interpretation of and Acting on PRO Scores in Clinical Practice Meeting Room 1+2, Second Floor

Moderator:

Claire Snyder, PhD, Johns Hopkins School of Medicine, Baltimore, MD, United States

Funded by Genentech: the authors had complete independence regarding the content and decision to present this symposium

There is increasing interest in using patient-reported outcome measures (PROMs) in clinical practice for individual patient management. PRO data can be used to promote personalized and patient-centered care, which we refer to as "PRO-cision Medicine." However, the use of PROMs in practice is limited by difficulties in interpreting PRO score meaning and in determining how to act on PRO score results. A number of projects have explored alternative methods for aiding PRO score interpretation and acting on PRO score results, but there is currently no standard approach to address these issues. We invited a series of papers that summarize methods that have been used to aid PRO score interpretation and to develop guidance for acting on PRO results (i.e., the "PRO-cision Medicine Methods Toolkit Paper Series"). The series includes eight papers describing methods for aiding score interpretation and eight papers describing how different PRO data collection systems address score interpretation and/or guidance for acting on the PRO results. In this symposium, we will summarize the different approaches featured in the paper series for both interpreting and acting on PRO scores and discuss the relative advantages and disadvantages of the alternative approaches. We will also identify cross-cutting themes across methods,

Saturday, 27 October

Scientific Program — Saturday, 27 October

highlighting areas of similarity and points of difference. Specifically, the moderator will first provide an overview of the project, and then we will present two brief abstracts: one summarizing approaches to aid PRO score interpretation and one summarizing approaches for developing guidance for acting on PRO score results. These brief presentations will be followed by an extended and interactive discussion with the audience, featuring a panel of paper series authors.

Individual Presenters:

Methods for aiding interpretation of PRO scores

Michael Brundage, MD, MSc, Queen's Cancer Research Institute, Kingston, ON, Canada

Methods for developing guidance for acting on PRO results

Albert Wu, MD, MPH, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, United States

Submitted on behalf of PRO-cision Medicine Toolkit Paper Authors

Symposium 7: Role of Health Preferences in Clinical Decision Making: The Past, Present, and Future

Meeting Room 9, Second Floor

Moderator:

Richard Skolasky, Sc.D. Johns Hopkins University, Baltimore, MD, United States

Health Preference Research (HPR) seeks to understand the value of health and health-related goods and services (i.e., patient preference). For most healthcare decisions, a choice must be made between the combination of available treatments and the positive and negative outcomes of each treatment. In the context of shared decision making, assessing patient preferences for possible health outcomes can help patients and healthcare providers choose treatments that fit the personal goals of each patient. One way to determine patient preference is to ascertain the health utilities for various health states. While health utilities are underutilized, they are important tools in aiding shared decision making between patients, caregivers and healthcare providers.

To be useful, health utilities should be specific to the clinical population for which they are being used. There are many ways to develop health utilities that assess patient preference using either direct or indirect methods. Direct methods involve asking patients to choose between health states (e.g., discrete choice experiments). Indirect methods involve using a patient reported outcome measure to generate health states that have been previously associated with a health utility (e.g., EQ-5D-5L or SF-6D). Once ascertained, health utilities can guide treatment discussion between patients and providers, allocation decisions among administrators and payers, and regulatory decisions by policymakers.

By understanding patient preferences, healthcare providers, administrators, and payers can provide services that meet the patients' needs. This symposium will describe the current state of HPR in the breast cancer literature and provide an example of a multi-attribute utility to assess quality adjusted life years. The speakers will also describe how HPR can be used by administrators and payers in healthcare resource allocation and by clinicians in making treatment recommendations.

Individual Presenters:

Improving Breast Cancer Care by Understanding Health Utilities: The Work Before the Work

Manraj Kaur, PhD(c), McMaster University, Hamilton, ON, Canada

Use of preferences to inform healthcare resource allocation

Donna Rowen, PhD, University of Sheffield, Sheffield, United Kingdom

MAUCa

Madeleine King, BSc (Hons), DipMedStat, PhD, University of Sydney, Sydney, Australia

Using Patient Reported Outcomes and Health Preferences to Improve Decision-Making in Orthopaedic Surgery

Amy Cizik, PhD, MPH, University of Washington, Seattle, WA, United States

Symposium 8: Methods for Scoring that Maximize Sensitivity to Treatment Effects: Three Major Pitfalls and How to Avoid Them Meeting Room 6, Second Floor

Moderator:

R. J. Wirth, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

Discussant:

Laura Lee Johnson, PhD, US FDA, Silver Spring, MD, United States

The paramount goal in patient reported outcome (PRO) development is to develop psychometrically precise scores that accurately characterize the effect of treatment on disease. Shortcomings in scoring methods can hinder our ability to detect treatment effects. In this symposium, we call upon our diverse PRO development experience to highlight:

1. three common barriers to construction of sensitive PRO endpoints, and
2. empirical methods useful in bypassing these barriers.

The three intricately-related barriers are:

1. Multidimensionality
2. Confounding effects [differential item functioning (DIF)]
3. Alternative scoring procedures

These barriers are intricately related because they each compose sequential hurdles to the final construction of optimally sensitive scores. Mishandling any one of these can decrease the validity and reliability of scores thereby negatively impacting the outcome of a study. Thus, success or failure of endpoints largely depends on how many of these barriers are encountered and how each is handled. Effectively managing each of these barriers is the key to generating scores that are optimized to detect significant treatment effects, should they truly exist. Emphasis will be made throughout on how each barrier and corresponding solution fits into current regulatory guidance and positions, and optimal strategies for balancing the three pillars of barrier, solution, and regulatory communication.

Rather than in-depth technical explanations of the three major barriers, the concepts are illustrated using a series of examples. These examples rely upon data simulated to emulate real PRO validations conducted by presenters. The simulated datasets allow the creation of “true” treatment effects. Invocation of such simulated data enables us to evaluate the ability of alternative procedures to recover this signal from the noise.

This symposium will provide attendees with a conceptual understanding of these common barriers and the current best practices for bypassing them. This understanding will permit attendees to be more effective consumers of PRO evidence, and translate to greater refinements in participants’ PRO research practices. It is the hope of the symposium panel that issues and techniques reviewed will help attendees construct maximally responsive PRO scores in their ongoing and future endpoint research.

Individual Presenters:

Multidimensional PRO Measures: Consequences for Treatment Effect Detection and Proposed Solutions

R. J. Wirth, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States

Ignoring Differential Item Functioning in PRO items: Score Bias, Lower Power, and Proposed Solutions

Charles Iaconangelo, PhD, Pharmerit International, New York, NY, United States

Techniques for Optimizing Score Sensitivity and Reliability

Daniel Serrano, PhD, Pharmerit International, Bethesda, MD, United States

Scientific Program — Saturday, 27 October

3:15 pm - 3:45 pm Refreshment Break Fitzwilliam Suites, Ground Floor

3:15 pm - 3:45 pm Saturday Poster Session II Lansdowne Room, Ground Floor

General Population

(3004) *Withdrawn*

(3006) Testing psychometric properties of the three short versions for the WHOQOL-OLD Module in Turkish national data pool.

Erhan Eser, prof, manisa celal bayar university, Yunus Emre, Turkey; Sultan Eser, Associate Professor, Balikesir University, Balikesir, Turkey

(3008) A Health Related Quality of Life Measure using Satisfaction with Life Domains and Life as a Whole

Frances Yang, Medical College of Georgia, Augusta, United States; Solon Kao, DDS, University of Missouri, Kansas City, MO, United States

(3010) Development and Validation of a “Complaints” Version of the revised Illness Perception Questionnaire

Holger Muehlan, University of Greifswald, Department Health & Prevention, Greifswald, Germany; Georg Schomerus, Professor, University Medicine Greifswald, Department of Psychiatry, Greifswald, Germany; Susanne Stolzenburg, Dipl.-Psych., University Medicine Greifswald, Department of Psychiatry, Greifswald, Germany; Marie Kendziora, Dipl.-Psych., University of Greifswald, Department Health & Prevention, Greifswald, Germany; Samuel Tomczyk, PhD, University of Greifswald, Department Health & Prevention, Greifswald, Germany; Silke Schmidt, Professor, University of Greifswald, Department Health & Prevention, Greifswald, Germany

(3012) Chronic diseases and self-perceived health status in the general population: Results of the Belgian Health Interview Survey 2013

Lisa Van Wilder, Ghent University, Ghent, Belgium; Delphine De Smedt, Professor, Ghent University, Ghent, Belgium; Els Clays, Professor, Ghent University, Ghent, Belgium; Brecht Devleeschauwer, DSc, Scientific Institute of Public Health, Brussels, Belgium; Johan Van der Heyden, PhD, Sciensano, Brussels, Belgium; Rana Charafeddine, DSc, Sciensano, Brussels, Belgium

Long-term Conditions

(3014) Living well while providing support: adaptation of the Long-Term Conditions Questionnaire (LTCQ) to develop LTCQ-Carer

Caroline Potter, DPhil, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Michele Peters, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom; Maureen Cundell, Oxford Health NHS Foundation Trust, Oxford, United Kingdom; Rupert McShane, MD, Oxford Health NHS Foundation Trust, Oxford, United Kingdom; Ray Fitzpatrick, PhD, Health Services Research Unit, University of Oxford, Oxford, United Kingdom

(3016) Examining chronic conditions, health burden and gender, and the mediating role of distress

Jae-Yung Kwon, University of British Columbia, Vancouver, British Columbia, Canada; Minjeong Park, University of British Columbia, Vancouver, British Columbia, Canada; Mohammad Ehsanul Karim, University of British Columbia, Vancouver, British Columbia, Canada; Richard Sawatzky, Trinity Western University, Langley, British Columbia, Canada

(3018) Measuring health-related quality of life in patients with chronic respiratory disease: reliability and construct validity of the SF-12

Magdalena Brandl, Medical Sociology, University of Regensburg, Regensburg, Germany; Susanne Brandstetter, PhD, Medical Sociology, University of Regensburg, Regensburg, Germany; Tamara Finger, Medical Sociology, University of Regensburg, Regensburg, Germany; Wiebke Fischer, Medical Sociology, University of Regensburg, Regensburg, Germany; Michael Pfeifer, MD, Department of Pneumology, Donaustauf Hospital, Regensburg, Germany; Christian Apfelbacher, PhD, Medical Sociology, University of Regensburg, Regensburg, Germany

(3020) Using Latent Variable Modeling to Study Multiple Comorbidity: An Application to the Co-Occurrence of Multiple Functional Disorders

James McGinley, PhD, Vector Psychometric Group LLC, Chapel Hill, NC, United States; **R. J. Wirth, PhD, Vector Psychometric Group, LLC, Chapel Hill, NC, United States;** J. P. Errico, JD, electroCore, LLC, Basking Ridge, NJ, United States; Peter Staats, MD, MBA, electroCore, LLC, Basking Ridge, NJ, United States; Richard Lipton, MD, Albert Einstein College of Medicine, Bronx, NY, United States

(3022) Evaluation of patients' self-care one month after hospitalization for decompensated heart failure

Debora Cristine Previde Teixeira da Cunha, PhD student, University of Sao Paulo, Ribeirão Preto, Brazil; Rafaela Oliveira Manzato, PhD student, University of Sao Paulo, Ribeirão Preto, Brazil; Eliane Nepomuceno, PhD Student, University of Sao Paulo, Ribeirão Preto, Brazil; Carina Marosti Dessotte, PhD, University of Sao Paulo, Ribeirão Preto, Brazil; Marcia Aparecida Ciol, PhD, University of Washington, Seattle, WA, United States; **Rosana Aparecida Spadoti Dantas, PhD, University of Sao Paulo, Ribeirão Preto, Brazil**

Musculoskeletal

(3024) A 10-years follow-up study of the total knee arthroplasty: factors influencing long-term health related quality of life outcomes

Amaia Bilbao, PhD, Research Unit, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain; Laura Ansola, MSc, Research Unit, Basurto University Hospital (Osakidetza), Bilbao, Spain; Juan Carlos Arenaza, MD, Traumatology and Orthopedic Surgery Service, Basurto University Hospital (Osakidetza) – REDISSEC, Bilbao, Spain; Isidoro Garcia, MD, Traumatology and Orthopedic Surgery Service, Galdakao-Usansolo Hospital (Osakidetza), Galdakao, Spain; Alejandro Bagueer, MD, Traumatology and Orthopedic Surgery Service, Donostia University Hospital (Osakidetza), Donostia, Spain; Ziortza Trancho, MSc, Research Unit, Basurto University Hospital (Osakidetza), Bilbao Spain; Jose Maria Quintana, MD, PhD, Research Unit, Galdakao-Usansolo Hospital (Osakidetza) – REDISSEC, Galdakao, Spain; Antonio Escobar, MD, PhD, Research Unit, Basurto University Hospital (Osakidetza) - REDISSEC, Bilbao, Spain

(3026) The latent structure of the Oxford Knee Score: learnings for validation employing big data

Andrew Trigg, Adelphi Values, Manchester, United Kingdom; Tom Palmer, PhD, Lancaster University, Lancaster, United Kingdom

(3028) Responsiveness of the EQ-5D-5L and EQ-5D-3L in patients following total hip or knee replacement

Xuejing Jin, PhD., MSc., School of Public Health, University of Alberta, Edmonton, Alberta, Canada; Fatima Al Sayah, PhD., School of Public Health, University of Alberta, Edmonton, Alberta, Canada; **Arto Ohinmaa, PhD., School of Public Health, University of Alberta, Edmonton, Alberta, Canada;** Deborah Marshall, PhD, Department of Community Health Sciences, University of Calgary., Calgary, Alberta, Canada; Jeffery Johnson, PhD, School of Public Health, University of Alberta, Edmonton, Alberta, Canada

(3030) Withdrawn

(3032) PROMIS physical and mental health measures are responsive to DMARD therapy in Rheumatoid Arthritis

Clifton Bingham, MD, Johns Hopkins, Baltimore, MD, United States; Alyssa Wohlfahrt, Brigham and Women's, Boston, MA, United States; Wendy Marder, MD, University of Michigan, Ann Arbor, MI, United States; Tuhina Neogi, MD, Boston University, Boston, MA, United States; Marcy Bolster, MD, Massachusetts General, Boston, MA, United States; Kristine Phillips, MD, Vanderbilt, Nashville, TN, United States; Yvonne Lee, MD, Northwestern, Chicago, IL, United States

(3034) Vigilance: an Unmeasured Patient-Centered Outcome for Ankle Reconstruction

Ellie Pinsker, BA&Sc, PhD cand., St. Michael's Hospital, Toronto, Ontario, Canada; Joanna Sale, PhD, St. Michael's Hospital, Toronto, Ontario, Canada; Monique Gignac, PhD, Institute of Work and Health, Toronto, Ontario, Canada; Timothy Daniels, MD, FRCSC, St. Michael's Hospital, Toronto, Ontario, Canada; **Dorcas Beaton, PhD, Institute of Work and Health, Toronto, Ontario, Canada**

(3036) Predictors of 5-year changes in Health-related Quality of Life in patients with Axial Spondyloarthritis

Gudrun Rohde, Professor, Faculty of Health and Sport Sciences, University of Agder, and Department of Clinical Research, Sorlandet Hospital, Kristiansand, Norway; Kari Hansen Berg, Faculty of Health and Sport Sciences, University of Agder, Kristiansand, Norway; Are Hugo Pripp, Oslo Centre of Biostatistics and Epidemiology Research Support Services Oslo University Hospital, Oslo, Norway; Anne Prøven, Department of Rheumatology, Martina Hansens Hospital, Bærum, Bærum, Norway; Glenn Haugeberg, Department of Clinical Research, Sorlandet Hospital HF, Kristiansand, Norway

(3038) Partners in Health (PIH) Scale Responses of Musculoskeletal Patients in a Student Clinic

Jane Mulcahy, Victoria University, Melbourne, Australia; Brett Vaughan, MHS, BSc, University of Melbourne, Melbourne, Australia

(3040) The factors associated with the development, progression and outcome of Dupuytren's disease treatment: a systematic review.

Julian Man, Imperial College London, London, United Kingdom; Luke Geoghegan, Imperial College London, London, United Kingdom; Abhilash Jain, Imperial College London, London, United Kingdom; Jeremy Rodrigues, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford, Oxford, United Kingdom

(3042) Site-specific patient-reported outcome measures for hand conditions: a systematic review of their development and psychometric properties

Justin Wormald, MBBS MRes MRCS, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, United Kingdom; Luke Geoghegan, BSc, Imperial College London, London, United Kingdom; Kyra Sierakowski, MD, Department of Plastic & Reconstructive Surgery, Flinders Medical Centre, Bedford Park, Adelaide, South Australia, Australia, Adelaide, Australia; Andrew Price, MA D.Phil FRCS(Orth), Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford, Oxford, United Kingdom; Michele Peters, BSc DipPsych MSc PhD, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom; Abhilash Jain, PhD FRCS(plast), Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford, Oxford, United Kingdom; Jeremy Rodrigues, BSc MBChB MSc PhD PGDip FRCS(Plast), Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences (NDORMS), University of Oxford, Oxford, United Kingdom

(3044) An International Qualitative Study to Develop a New Patient-Reported Outcome Instrument for Hand conditions: The HAND-Q.

Kyra Sierakowski, MD, MS, Flinders University, Adelaide, Australia; Andrea Pusic, MD, MPH, FACS, Brigham and Women's Hospital, Harvard Medical School, Boston, MA, United States; Kathleen Evans Sanchez, BSc(Hons), College of Medicine & Public Health, Flinders University, Adelaide, Australia; Philip Griffin, MBBS, FRACS, Department of Plastic & Reconstructive Surgery, Flinders Medical Centre, Adelaide, Australia; Gregory Bain, MBBS, FRACS, PhD, College of Medicine & Public Health, Flinders University, Adelaide, Australia; Donald Lalonde, MD, MSc, FRCSC, Dalhousie University, Saint John, New Brunswick, Canada; Nicola Dean, MBChB, PhD, FRCS, FRACS, Department of Plastic & Reconstructive Surgery, Flinders Medical Centre, Adelaide, Australia; Anne Klassen, DPhil, McMaster University, Hamilton, Ontario, Canada

(3046) Measuring elbow functioning - Cross-cultural adaptation and validation of the Portuguese version of the Oxford Elbow Score (OES)

Luís Cavalheiro, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Ana Alves, PT, MSc, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Rui Soles Gonçalves, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Pedro Lopes Ferreira, PhD, University of Coimbra, Centre for Health Studies and Research, Coimbra, Portugal

(3048) Item Response Theory Linking of the PROMIS and FAAM Instruments

Man Hung, University of Utah, Salt Lake City, UT, United States; Judith Baumhauer, MD, University of Rochester Medical School, Rochester, NY, United States; **Shirley Hon, University of Utah, Salt Lake City, UT, United States;** Maren Voss, ScD, University of Utah, Salt Lake City, UT, United States; Wei Li, University of Utah, Salt Lake City, UT, United States; Julie Xu, University of Utah, Salt Lake City, UT, United States; Bianca Ruiz, University of Utah, Salt Lake City, UT, United States; Megan Rosales, University of Utah, Salt Lake City, UT, United States; Jerry Bounsanga, BS, University of Utah, Salt Lake City, UT, United States; Weicong Su, University of Utah, Salt Lake City, UT, United States; Charles Saltzman, MD, University of Utah, Salt Lake City, UT, United States

(3050) Withdrawn

(3052) Disabilities of the Arm, Shoulder and Hand questionnaire in Portuguese patients with shoulder problems - cross-cultural adaptation and validation

Rui Soles Gonçalves, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Joseph Dos Santos, PT, MSc, Polytechnic Institute of Castelo Branco, College of Health Dr. Lopes Dias, Castelo Branco, Portugal; Joana Oliveira Rosado, PT, MSc, Rainha Santa Isabel Center, Diocesan Caritas of Coimbra, Coimbra, Portugal; Luís Manuel Cavalheiro, PT, PhD, Polytechnic Institute of Coimbra, Coimbra Health School, Coimbra, Portugal; Pedro Lopes Ferreira, PhD, University of Coimbra, Centre for Health Studies and Research, Coimbra, Portugal

(3054) Guideline-based Care Improves Outcomes that Matter to Patients with Rheumatoid Arthritis

Susan Bartlett, McGill University, Montreal, Quebec, Canada; Orit Schieir, University of Toronto, Montreal, Quebec, Canada; Marie-France Valois, McGill University, Montreal, Quebec, Canada; Carol Hitchon, University of Manitoba, Winnipeg, Quebec, Canada; Janet Pope, Western University, London, Ontario, Canada; Gille Boire, University of Sherbrooke, Sherbrooke, Quebec, Canada; Boulos Haraoui, Institute de Rheumatologie, Montreal, Quebec, Canada; Edward Keystone, Mt. Sinai Hospital, Toronto, Ontario, Canada; Diane Tin, Southlake Regional Health Center, Newmarket, Ontario, Canada; Carter Thorne, Southlake Regional Health Center, Newmarket, Ontario, Canada; Vivian Bykerk, Hospital for Special Surgery, New York, NY, United States; submitted on behalf of CATCH Investigators

Older Adults

(3056) Understanding the patient experience of presbyopia and identification of patient-reported outcome assessments: a literature review

Garima Sharma, Novartis Healthcare Private Limited, Hyderabad, India; Daniel Viriato, Novartis Pharma AG, Basel, Switzerland; Christel Naujoks, Novartis Pharma AG, Basel, Switzerland; Francesco Patalano, Novartis Pharma AG, Basel, Switzerland; Sarah Kilgariff, Adelphi Values, Cheshire, United Kingdom; James S. Wolffsohn, Aston University, Birmingham, United Kingdom

(3058) Cognitive functioning is not associated with measurement bias in frail seniors' self-reported physical and mental health status

Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Ayumi Sasaki, M.A., University of British Columbia, Vancouver, British Columbia, Canada; Rozanne Wilson, PhD, Trinity Western University, Vancouver, British Columbia, Canada; Lena Cuthbertson, BHScOT, MEd, British Columbia Ministry of Health/Providence Health Care, Vancouver, British Columbia, Canada; Lillian Parsons, MPH, Providence Health Care, Vancouver, British Columbia, Canada; Richard Sawatzky, PhD, Trinity Western University & Centre for Health Evaluation and Outcome Sciences, Langley, British Columbia, Canada

(3060) Withdrawn

(3062) Quality of life, health and participation of older adults: a study on Active Aging in Spain

Maria João Forjaz, PhD, Institute of Health Carlos III, Madrid, Spain; Victor Quiros-Gonzlez, MD, MPH, Department of Preventive Medicine, University Hospital of Salamanca, Salamanca, Spain; Carmen Rodriguez-Blazquez, PhD, 3.National Center of Epidemiology, Institute of Health Carlos III and CIBERNED, Madrid, Spain; Elena Pola, MD, MPH, Department of Preventive Medicine, University Hospital of Móstoles, Madrid, Spain; Alba Ayala, PhD, Institute of Economics, Geography and Demography (IEGD); Spanish National Research Council (CSIC), Madrid, Spain; Fermina Rojo-Perez, PhD, Institute of Economics, Geography and Demography (IEGD); Spanish National Research Council (CSIC), Madrid, Spain; Gloria Fernandez-Mayoralas, PhD, Institute of Economics, Geography and Demography (IEGD); Spanish National Research Council (CSIC), Madrid, Spain

(3064) Development and evaluation of a patient-reported outcome measure for patients with venous leg ulcers

Rasa Ruseckaite, Monash University, Melbourne, Australia; Claudia Rutherford, University of Sydney, Sydney, Australia; Peter Franks, Centre for Research & Implementation of Clinical Practice, London, United Kingdom; Rosemary McGuinness, Monash University, Melbourne, Australia; Louise Turnour, Monash University, Melbourne, Australia; Victoria Team, Monash University, Melbourne, Australia; Carolina Weller, Monash University, Melbourne, Australia

Patient Satisfaction and Experience

(3066) *Withdrawn*

(3068) Assessing Methods of Content Validity Elicitation: the Treatment Satisfaction Questionnaire for Medication

Ana Maria Rodriguez Leboeuf, PhD MSc BScPT, IQVIA, Montreal, Quebec, Canada; Paul Williams, MPH, BSc, IQVIA, Paris, France; Eric Gemmen, MSc, BSc, IQVIA, Washington, DC, United States; Alexandra Palmer, MA BA, IQVIA, La Quinta, CA, United States; Louise Parmenter, PhD, MPH, BSc, IQVIA, London, United Kingdom

(3070) Self-related satisfaction associated to bed bath of bedridden inpatients in Latin America: integrative review of the literature.

Beatriz Conacci, Bachelors in Nursing, Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo, Ribeirão Preto, Brazil; Valeria Andrade, Master, Federal University of Triângulo Mineiro, Uberaba, Brazil; Fernanda Karla Nascimento, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Viviane Romeiro, Bachelor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil; Monica Mombelli, Master, Centro Universitário União Dinâmica das Cataratas, Foz do Iguaçu, Brazil; Claudia Benedita dos Santos, Doctor, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, Brazil

(3072) Assessment of patient experience and satisfaction in an orthogeriatric ward

Charlotte Abrahamsen, Assistant professor, Department of Orthopaedic Surgery, Kolding Hospital a part of Lillebaelt Hospital, Kolding, Denmark; Eva Draborg, Associated professor, University of Southern Denmark, Odense, Denmark; Birgitte Nørgaard, Associated professor, University of Southern Denmark, Odense, Denmark

(3074) Feasibility of an online-only method of generating subject usability and cognitive debriefing data for electronically administered questionnaires: an example using the Treatment Satisfaction Questionnaire for Medication (TSQM)

Paul Williams, MPH, IQVIA, Paris, France; Ana Maria Rodriguez, PhD MSc PT BSc, IQVIA, Madrid, Spain; Alexandra Palmer, MA, IQVIA, Laquinta, CA, United States; Eric Gemmen, MA, IQVIA, Rockville, MD, United States; Louise Parmenter, PhD, IQVIA, Reading, United Kingdom

Quality Standards and Core Outcome Sets

(3076) Critical appraisal within systematic reviews of measurement properties: A review of available instruments.

Kimberley Cullen, Institute for Work & Health, Toronto, Ontario, Canada; **Dorcas Beaton, Institute for Work & Health, Toronto, Ontario, Canada;** Zahi Touma, University of Toronto Lupus Clinic, Toronto Western Hospital, Toronto, Ontario, Canada; Carol Kennedy, Health Quality Ontario, Toronto, Ontario, Canada; Sheilah Hogg-Johnson, Institute for Work & Health; Canadian Memorial Chiropractic College, Toronto, Ontario, Canada; Peter Smith, Institute for Work & Health, Toronto, Ontario, Canada; Dwayne Van Eerd, Institute for Work & Health, Toronto, Ontario, Canada; Daniela Milani, Universidade Estadual do Centro-Oeste (Unicentro), Guarapuava, Brazil; Lisa Engel, University of Toronto Lupus Clinic, Toronto Western Hospital, Toronto, Ontario, Canada; Emma Irvin, Institute for Work & Health, Toronto, Ontario, Canada; Quenby Mahood, Institute for Work & Health, Toronto, Ontario, Canada; Kathleen Bingham, Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada; Jocelyn Dollack, Institute for Work & Health, Toronto, Ontario, Canada; Elizabeth Sled, Cedarville University, Cedarville, OH, United States

(3078) The Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID) is now sixteen years old: It is time to tell the story!

Laure-Lou Perrier, Mapi Research Trust, Lyon, France; Florian Aubert, Mapi Research Trust, Lyon, France; Vanessa Martel, Mapi Research Trust, Lyon, France; **Katrin Conway, Mapi Research Trust, Lyon, France;** Catherine Acquadro, Mapi Research Trust, Lyon, France

(3080) A new online system for the standardized appraisal of PRO instruments: the EMPRO platform

Montserrat Ferrer, IMIM-Hospital del Mar Medical Research Institute, Barcelona, Spain; Carlos García-Forero, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Olatz Garin, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Yolanda Pardo, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Gemma Vilagut, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Itxaso Alayo, CIBER Epidemiología y Salud Pública (CIBERESP), Barcelona, Spain; Víctor Zamora, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Cristina Oriol, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; Jose M. Valderas, MD, MPH, PhD, University of Exeter, Exeter, United Kingdom; Jordi Alonso, IMIM- Hospital del Mar Medical Research Institute, Barcelona, Spain; submitted on behalf of the Empro Group

(3082) Development and Assessment of Common Quality Standards for Clinical Outcome Evaluation Scale

Jiaxin Xiao, First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangzhou, China; **Zhengkun Hou, First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangzhou, China;** Feng-bin Liu, First Affiliated Hospital of Guangzhou University of Chinese Medicine, Guangzhou, China

Rehabilitation

(3084) Clinical Utilization of the SCI-QOL Measurement System during Inpatient Rehabilitation

Allen Heinemann, PhD, Shirley Ryan AbilityLab / Northwestern University, Chicago, IL, United States; Linda Ehrlich-Jones, PhD, Shirley Ryan AbilityLab, Chicago, IL, United States; Kristian Nitsch, PhD, Illinois Institute of Technology, Chicago, IL, United States; Leah Malamut, BA, Shirley Ryan AbilityLab, Chicago, IL, United States; Pam Kisala, MA, University of Delaware, Newark, DE, United States

(3086) Withdrawn

(3088) Effect of medical social rehabilitation in terms of QoL in survivors with childhood brain tumors and their parents

Grigory Tseitlin, Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, Moscow, Russia; Alexander Rummyantsev, Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, Moscow, Russia; Alexander Karelin, Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, Moscow, Russia; Marina Kokoreva, Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, Moscow, Russia; Irina Borodina, Dmitry Rogachev National Medical Research Center of Pediatric Hematology, Oncology and Immunology, Moscow, Russia; Tatiana Nikitina, Clinic of High Medical Technologies named after N.I. Pirogov, Saint-Petersburg State University, Saint-Petersburg, Russia; Anna Zinkovskaya, Multinational Center for Quality of Life Research, Saint-Petersburg, Russia; Natalia Porfir'eva, Multinational Center for Quality of Life Research, Saint-Petersburg, Russia; **M. Sam Salek, School of Life and Medical Sciences, University of Hertfordshire, Hatfield, United Kingdom;** Tatiana Ionova, Clinic of High Medical Technologies named after N.I. Pirogov, Saint-Petersburg State University, Saint-Petersburg, Russia

(3090) Preaching to the Choir? Supportive Care Uptake and Patient Experience with Head and Neck Cancer

Jolie Ringash, MD, The Princess Margaret Cancer Centre and The University of Toronto, Toronto, Ontario, Canada; Nauman Malik, MD, The Princess Margaret Cancer Centre and The University of Toronto, Toronto, Ontario, Canada; Shao Hui Huang, MD, The Princess Margaret Cancer Centre and The University of Toronto, Toronto, Ontario, Canada; Andrea Gomes, MSc, The Princess Margaret Cancer Centre, Toronto, Ontario, Canada; Raymond Jang, MD, The Princess Margaret Cancer Centre and The University of Toronto, Toronto, Ontario, Canada; Eric Monteiro, MD, The Princess Margaret Cancer Centre and The University of Toronto, Toronto, Ontario, Canada; Joanne Pun, BSc, The Princess Margaret Cancer Centre, Toronto, Ontario, Canada; Maureen McQuestion, The Princess Margaret Cancer Centre, Toronto, Ontario, Canada

(3092) Computerized Adaptive Testing to Direct Delivery of Hospital-based Rehabilitation: Item-bank generation and data collection

Kathleen Yost, PhD, Mayo Clinic, Rochester, MN, United States; Alan Jette, PhD, Boston University, Boston, MA, United States; Chun Wang, PhD, University of Minnesota, Minneapolis, MN, United States; David Weiss, PhD, University of Minnesota, Minneapolis, MN, United States; Andrea Cheville, MD, Mayo Clinic, Rochester, MN, United States

(3094) Clarification of health-related QOL related factors for breast cancer patients - Influence on the range of shoulder joint movement and postoperative subjective symptom -

Tetsuya Sano, Master of Science, Department of Rehabilitation, Suzukake Health Care Hospital, Iwata, Japan; Ryota Izumi, Doctor of Philosophy, Department of Occupational Therapy, Seirei Christopher University, Hamamatsu, Japan; Motohiro Ogawa, Master of Science, Department of Rehabilitation, Hamamatsu University School of Medicine, Hamamatsu, Japan; Shinichi Noto, Doctor of Philosophy, Department of Occupational Therapy, Niigata University of Health and Welfare, Niigata, Japan

Utilities

(3096) Methodology for Developing Preference-Based Measures from the Patient's Perspective: An Example from the Development of a Weight Related Quality of Life Index

Ana-Maria Moga, Faculty of Medicine, School of Physical & Occupational Therapy, McGill University, Montreal, Quebec, Canada; Nancy E. Mayo, PhD, James McGill Professor, Faculty of Medicine, School of Physical & Occupational Therapy, McGill University, Montreal, Quebec, Canada; Sara Ahmed, PhD, Faculty of Medicine, School of Physical & Occupational Therapy, McGill University, Montreal, Quebec, Canada; Laurie Twells, PhD, Memorial University of Newfoundland- School of Pharmacy & Faculty of Medicine, St. John's, Newfoundland and Labrador, Canada

(3098) Preferences for life domains differ across countries – findings from the QLU-C10D valuation project

Georg Kemmler, PhD, Innsbruck Medical University, Innsbruck, Austria; Eva Gamper, PhD, Innsbruck Medical University, Innsbruck, Austria; Richard Norman, PhD, Curtin University, Perth, Australia; Madeleine King, Prof., University of Sydney, Sydney, Australia; Bernhard Holzner, Prof., Innsbruck Medical University, Innsbruck, Austria

(3100) Extending the QALY: Developing and testing the proposed items for a new generic measure - results from qualitative review and face validity with patients, social care users and carers

Janice Connell, University of Sheffield, Sheffield, United Kingdom; **Jill Carlton, University of Sheffield, Sheffield, United Kingdom;** Tessa Peasgood, University of Sheffield, Sheffield, United Kingdom; Clara Mukuria, University of Sheffield, Sheffield, United Kingdom; John Brazier, University of Sheffield, Sheffield, United Kingdom; Federico Augustovski, Institute for Clinical Effectiveness and Health Policy, Buenos Aires, Argentina; Maria Belizan, Institute for Clinical Effectiveness and Health Policy, Buenos Aires, Argentina; Lidia Engel, Deakin University, Melbourne, Australia; Wolfgang Greiner, Bielefeld University, Bielefeld, Germany; Lisa Hanna, Deakin University, Melbourne, Australia; Kristina Ludwig, Bielefeld University, Bielefeld, Germany; Andrea Monteiro, University of Illinois at Chicago, Chicago, IL, United States; Brendan Mulhern, University of Technology Sydney, Sydney, Australia; Luo Nan, National University of Singapore, Singapore, Singapore; Simon Pickard, University of Illinois at Chicago, Chicago, IL, United States

Scientific Program — Saturday, 27 October

(3102) Mapping of renal symptom severity scores into utility scores

Manuel Monroy, Universidad Autónoma de Madrid, Madrid, Spain; **Miguel A. Ruiz, PhD, Universidad Autónoma de Madrid, Madrid, Spain**; Javier Rejas, MD, PhD, Universidad Carlos III, Madrid, Spain; Javier Soto, MD, PhD, Universidad Carlos III, Madrid, Spain; Juan C Julian, BA, Fundación Nacional ALCER, Madrid, Spain

(3104) A discrete choice experiment to understand preferences of colorectal cancer patients towards organizational characteristics of the chemotherapy outpatient service. Preliminary results

Rosalba Rosato, Assistant Professor PhD, Università di Torino, Torino, Italy; Eva Pagano, Unit of Clinical Epidemiology, "Città della Salute e della Scienza" Hospital, Turin, Italy; Daniela Di Cuonzo, Department of Psychology, University of Turin, Turin, Italy; Laura Franchini, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology, "Città della Salute e della Scienza" Hospital, Turin, Italy; Giuliana Ritorto, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology, "Città della Salute e della Scienza" Hospital, Turin, Italy; Marcello Zanini, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology, "Città della Salute e della Scienza" Hospital, Turin, Italy; Patrizia Racca, SSCVD ColoRectal Cancer Unit-Oncologia 1- Department of Oncology, "Città della Salute e della Scienza" Hospital, Turin, Italy

3:50 pm - 5:20 pm **Concurrent Oral Sessions**

Oral Session 301: Cancer Survivorship Meeting Room 1+2, Second Floor

Session Chair: Kathleen Yost, PhD, United States

3:55 pm - 4:12 pm (301.1) Phase I and II development of an EORTC QOL cancer survivorship assessment strategy: issue generation and construction of provisional questionnaires

Marieke van Leeuwen, PhD, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Neil Aaronson, PhD, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; Lonke van de Poll-Franse, PhD, Division of Psychosocial Research & Epidemiology, The Netherlands Cancer Institute, Amsterdam, Netherlands; submitted on behalf of The European Organisation for Research and Treatment of Cancer Quality of Life Group

4:13 pm - 4:30 pm (301.2) Relationship between Patient-Reported Bother from Side effects, Adverse Events and Survival in Advanced Ovarian Cancer

Lari Wenzel, University of California, Irvine, Irvine, CA, United States; Kathryn Osann, PhD, University of California, Irvine, Irvine, CA, United States; David Cella, PhD, Northwestern University, Evanston, IL, United States; Giulia Fulci, PhD, University of Alabama, Birmingham, AL, United States; Michael Birrer, MD, PhD, University of Alabama, Birmingham, AL, United States

4:31 pm - 4:48 pm (301.3) Quality of life, spiritual well-being, and self-compassion: Finding 'peace of mind' among cancer survivors

Hayley Whitford, University of South Australia Cancer Research Institute, Adelaide, Australia; John Salsman, PhD, Department of Social Sciences and Health Policy, Wake Forest School of Medicine, Winston-Salem, NC, United States; Ian Olver, MD, PhD, FRACP, University of South Australia Cancer Research Institute, Adelaide, Australia

4:49 pm - 5:06 pm (301.4) Non-compensatory analysis of quality of life in breast cancer survivors using multivariate hidden Markov modeling

Edward Ip, Wake Forest School of Medicine, Winston-Salem, NC, United States; Sarah Marshall, MPH, Wake Forest School of Medicine, Winston-Salem, NC, United States; Beverly Levine, PhD, Wake Forest School of Medicine, Winston-Salem, NC, United States; Nancy Avis, PhD, Wake Forest School of Medicine, Winston-Salem, NC, United States

Oral Session 302: Surveys and Longitudinal Studies Meeting Room 6, Second Floor

Session Chair: Deborah M. Miller, PhD, United States

3:55 pm - 4:12 pm (302.1) Predictors of quality of life in adults with coeliac disease in England

Michele Peters, PhD, University of Oxford, Oxford, United Kingdom; Helen Crocker, DPhil, University of Oxford, Oxford, United Kingdom; Mara Violato, PhD, University of Oxford, Oxford, United Kingdom; Thomas Lewis, BSc, University of Oxford, Oxford, United Kingdom; Crispin Jenkinson, DPhil, University of Oxford, Oxford, United Kingdom;

4:13 pm - 4:30 pm (302.2) The association of health, housing and social factors with subjective quality of life in homeless and vulnerably housed individuals

Anne Gadermann, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Lara Russell, PhD, Providence Health Care, Vancouver, British Columbia, Canada; Monica Norena, MSc, Providence Health Care, Vancouver, British Columbia, Canada; Anita Hubley, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Susan Farrell, PhD, University of Ottawa, Ottawa, Ontario, Canada; Stephen Hwang, MD, University of Toronto, Toronto, Ontario, Canada; Anita Palepu, MD, University of British Columbia, Vancouver British Columbia, Canada

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4:31 pm - 4:48 pm (302.3) Prediction models for functional outcome after trauma: a prospective cohort study

Leonie de Munter, MSc, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands; Suzanne Polinder, PhD, Department of Public Health, Erasmus Medical Centre, Rotterdam, the Netherlands, Rotterdam, Netherlands; Cornelis van de Ree, MD, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, the Netherlands, Tilburg, Netherlands; Nena Kruithof, MSc, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, Netherlands, Tilburg, Netherlands; Ewout Steyerberg, PhD, Department of Public Health, Erasmus Medical Centre, Rotterdam, the Netherlands AND Department of Biomedical Data Sciences, Leiden University Medical Center, Leiden, The Netherlands, Rotterdam, Netherlands; Mariska de Jongh, PhD, Department Trauma TopCare, Elisabeth-TweeSteden Hospital, Tilburg, the Netherlands AND Brabant Trauma Registry, Network Emergency Care Brabant, the Netherlands, Tilburg, Netherlands

4:49 pm - 5:06 pm (302.4) Factors associated with community ambulation in adults aged 45-85 – the Canadian Longitudinal Study on Aging

Ruth Barclay, PhD, College of Rehabilitation Sciences, University of Manitoba, Winnipeg, Manitoba, Canada; Sandra Webber, PhD, College of Rehabilitation Sciences, University of Manitoba, Winnipeg, Manitoba, Canada; Jacquie Ripat, PhD, College of Rehabilitation Sciences, University of Manitoba, Winnipeg, Manitoba, Canada; Robert Tate, PhD, Department of Community Health Sciences, University of Manitoba, Winnipeg, Manitoba, Canada

Oral Session 303: Heterogeneity and Meaning in Measurement Meeting Room 9, Second Floor

Session Chair: Joanne Greenhalgh, PhD, United Kingdom

3:55 pm - 4:12 pm (303.1) Comprehension of patient-reported outcome items by older adult patients with mild or moderate cognitive impairment

Antonia Bennett, University of North Carolina, Chapel Hill, NC, United States; Sarah Drier, MPH, University of North Carolina, Chapel Hill, NC, United States; Kimberly Light, University of North Carolina, Chapel Hill, NC, United States; Michelle Johnson, University of North Carolina, Chapel Hill, NC, United States; Mary Mouw, MD MPH, University of North Carolina, Chapel Hill, NC, United States; Bryce Reeve, PhD, Duke University, Durham, NC, United States; John Kizer, MD, University of North Carolina, Chapel Hill NC, United States; Darren Dewalt, MD MPH, University of North Carolina, Chapel Hill, NC, United States

4:13 pm - 4:30 pm (303.2) Inter-individual differences in the understanding of health-related quality of life in patients with chronic diseases: A vignette approach

Janine Topp, University Medical Center Hamburg, Hamburg, Germany; Christine Blome, University Medical Center Hamburg, Hamburg, Germany; Chrsitoph Heesen, University Medical Center Hamburg, Hamburg, Germany; Matthias Augustin, University Medical Center Hamburg, Hamburg, Germany; Jana Poettgen, University Medical Center Hamburg, Hamburg, Germany; Valerie Andrees, University Medical Center Hamburg, Hamburg, Germany

4:31 pm - 4:48 pm (303.3) Accommodating heterogeneity to improve measurement validity in large population health surveys

Richard Sawatzky, Trinity Western University & Centre for Health Evaluation and Outcome Sciences, Langley, British Columbia, Canada; Lara Russell, PhD, Centre for Health Evaluation and Outcome Sciences, Vancouver, British Columbia, Canada; Tolulope Sajobi, PhD, University of Calgary, Calgary, Alberta, Canada; Anne Gadermann, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Juxin Liu, PhD, University of Saskatchewan, Saskatoon, Saskatchewan, Canada; Bruno Zumbo, PhD, University of British Columbia, Vancouver, British Columbia, Canada; Lisa Lix, PhD, University of Manitoba, Winnipeg Manitoba, Canada

4:49 pm - 5:06 pm (303.4) Deciding when a child is depressed: Content heterogeneity in PROMs for children and adolescent depression

Anna Vilar, Institut de Neuropsiquiatria i Addiccions (INAD) - Parc de Salut Mar, Barcelona, Spain; Gemma Vilagut, PhD, Health Services Research Unit, IMIM - Hospital del Mar Medical Research Institute, Barcelona, Spain; Maria Jesús Blasco, MPsych(Clin), Universitat Pompeu Fabra (UPF), Department of Experimental and Health Sciences, Barcelona, Spain; Laura Ballester, MPsych(Clin), Health Services Research Unit, IMIM - Hospital del Mar Medical Research Institute, Barcelona, Spain; Santiago Batlle-Vila, MPsych(Clin), Institut de Neuropsiquiatria i Addiccions (INAD) - Parc de Salut Mar, Barcelona, Spain; Mireia Romero, MPsych(Clin), Institut de Neuropsiquiatria i Addiccions (INAD) - Parc de Salut Mar, Barcelona, Spain; Jordi Alonso, PhD, Health Services Research Unit, IMIM - Hospital del Mar Medical Research Institute; CIBER Epidemiologia y Salud Pblca (CIBERESP), Barcelona, Spain; **Carlos G Forero, PhD, CIBER Epidemiologia y Salud Pública (CIBERESP), Barcelona, Spain**

Scientific Program — Saturday, 27 October

Oral Session 304: Qualitative Methods in Instrument Development Pembroke & Herbert, Ground Floor

Session Chair: Kathy Lasch, PhD, United States

3:55 pm - 4:12 pm (304.1) Quality of life priorities for children with disabilities: contrasting child and parent perspectives

Elena Swift, University of Melbourne, Carlton, Australia; Lisa Gibbs, PhD, University of Melbourne, Melbourne, Australia; Dinah Reddihough, MD, Royal Children's Hospital, Melbourne, Australia; Elise Davis, PhD, University of Melbourne, Melbourne, Australia; Andrew Mackinnon, PhD, University of Melbourne, Melbourne, Australia

4:13 pm - 4:30 pm (304.2) Qualitative evidence on the content validity of EORTC QLQ-C30: Initial findings

Kim Cocks, Adelphi Values Ltd, Bollington, United Kingdom; Chloe Tolley, BSc, Adelphi Values Ltd, Bollington, United Kingdom; Laura Grant, MSc, Adelphi Values Ltd, Bollington, United Kingdom; Jane Wells, MSc, Adelphi Values Ltd, Bollington, United Kingdom; Sally Wheelwright, University of Southampton, Southampton, United Kingdom; Krzysztof Tomaszewski, MD, PhD, Jagiellonian University Medical College, Krakow, Poland; Mogens Gronvold, PhD, Bispebjerg Hospital, Copenhagen, Denmark; Andrew Bottomley, PhD, EORTC Headquarters, Brussels, Belgium; Deborah Fitzsimmons, PhD, University of Swansea, Wales, United Kingdom; Galina Velikova, PhD, University of Leeds, Leeds, United Kingdom; Simone Oerlemans, PhD, University of Amsterdam, Amsterdam, Netherlands; Monica Pinto, MD, Istituto Nazionale dei Tumori, Milan, Italy; Colin Johnson, MChir FRCS, University of Southampton, Southampton, United Kingdom; submitted on behalf of on behalf of the EORTC Quality of Life Group

4:31 pm - 4:48 pm (304.3) Determinants of quality of life in atrial fibrillation and the clinical value of measurement: Focus group Results: from the RATE-AF trial led by a Patient & Public Involvement team

Jacqueline Jones, Patient & public involvement team, RATE-AF trial, Birmingham, United Kingdom; Mary Stanbury, Patient & public involvement team, RATE-AF trial, Birmingham, United Kingdom; Jonathan Mathers, Institute of Applied Health Research & Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; Melanie Calvert, Institute of Applied Health Research & Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom; **Dipak Kotecha, Institute of Cardiovascular Sciences & Centre for Patient Reported Outcomes Research, University of Birmingham, Birmingham, United Kingdom**

4:49 pm - 5:06 pm (304.4) Development of a patient-centered conceptual model of fatigability

Anna Kratz, PhD, University of Michigan, Ann Arbor, MI, United States; Noelle Carlozzi, PhD, University of Michigan, Ann Arbor, MI, United States; Tiffany Braley, MD, University of Michigan, Ann Arbor, MI, United States; Neil Basu, MBChB MRCP PhD, University of Aberdeen, Aberdeen, United Kingdom; Susan Murphy, ScD OTR, University of Michigan, Ann Arbor, MI, United States

7:00 pm - 10:00 pm Closing Dinner (Ticket Required) Royal College of Physicians Ireland

An exclusive venue in the heart of Dublin opened in 1860, No.6 Kildare Street has been home to the Royal College of Physicians of Ireland for over 150 years and has a unique collection of artifacts and antiques which reflect the rich history of the College.

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Saturday, 27 October

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Exhibit #2

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Exhibit #3

HealthMeasures consists of four precise, flexible, and comprehensive measurement systems, PROMIS®, Neuro-QoL, ASCQ-Me®, and NIH Toolbox®. These measurement systems assess physical, mental, and social health, symptoms, well-being and life satisfaction; along with sensory, motor, and cognitive function. Visit the HealthMeasures booth where we feature educational materials, opportunities to speak with a HealthMeasures scientist, and guidance on how to integrate these measurement systems into your work. For more information, visit: HealthMeasures.net.



Exhibit #5

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Exhibit #4

Mapi Research Trust is a non-profit organization promoting

the use of Clinical Outcomes Assessments (COAs) in studies, and encouraging exchanges in the Patient-Centered Outcomes field between academics, pharmaceutical companies, and international organizations around the world. Through two unique databases (PROQOLID & PROLabels), developed and constantly updated by Mapi Research Trust research professionals, we not only exchange the latest health outcomes information, but also create vital links among those at every level of Patient-Centered Outcomes studies. We maintain the world's largest library devoted exclusively to Clinical Outcomes Assessments (COA), and make its wealth of information available to those who need it most.



Exhibit #1

Springer is a leading publisher of books, journals, electronic products and considered the largest Open Access publisher. Visit the Springer booth where we will be highlighting ISOQOL's two journal publications: **Quality of Life Research** (Impact Factor: 2.392) and the newly launched Open Access **Journal of Patient-Reported Outcomes**. For more information please visit www.springer.com and www.springeropen.com.



Exhibit #6

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555 E. Wells St., Suite 1100, Milwaukee, WI 53202
Tel: 1.414.918.9797 | Fax: 1.414.276.3349
info@isoqol.org