The 6th Meeting of the International Academy of Health Preference research

Pre-meeting Symposium

Thursday, 6 July 2017 from 13:00 to 17:00

Scientific Meeting

Friday, 7 July 2017 from 08:00 to 17:30

Jonathan Spack Community Conference Center
at The NonProfit Center

89 South Street
Boston, Massachusetts, USA

Chaired by **Juan Marcos González Sepulveda, PhD** and **F. Reed Johnson, PhD**, this half-day symposium and full-day meeting will provide a forum to present and discuss innovative developments in health preference research. The symposium will focus on "**Preference Evidence for Regulatory Decisions**" and include a series of contemporary case studies demonstrating the policy relevance of preference research. The scientific meeting will include peer-reviewed podium presentations, lunch (with poster session), and a business session.

PROGRAM

Pre-Meeting Symposium, Thursday, 6 July 2017 from 13:00 to 17:30

The NonProfit Center, 89 South Street, Boston, Massachusetts, USA

13:00-13:10 Welcome

Meeting Chairs: **Juan Marcos González Sepulveda** [α] and **F. Reed Johnson**[α]

13:10-14:40 Session 1 – Case Studies, Juan Marcos González Sepulveda [α]

Be Careful What You Ask For: Quantifying and Using Patients' Benefit-Risk Tradeoff Preferences, **F. Reed Johnson** [α]
Preference Studies for Regulatory Applications: Lessons from the Field, **Bennett Levitan**
Preference Studies from an Industry Perspective: What Academics and Patients Should Know, **Rebecca A. Noel**

14:40-15:00 Mid-Afternoon Break

15:00-16:00 Session 2 – Case Studies, F. Reed Johnson[α]

Impact of Preference Evidence on Regulators: The Emerging Duchenne Experience, **Holly Peay**
Evaluation and Use of Patient Preference Evidence to Inform Regulatory Decision Making at FDA Center for Devices and Radiological Health (CDRH) and Center for Drug Evaluation and Research (CDER), **Martin Ho** and **Vishal Bhatnagar**

16:00-17:15 Session 3 – Panel Discussion, All

Topic #1: Whose preferences should be considered and how should they be considered?
Topic #2: In the absence of regulatory guidance on identifying acceptable methods for quantifying stated preferences, how should researchers think about "regulatory-quality" approaches?
Topic #3: What are the greatest challenges in collecting, submitting, and evaluating quantitative preference information in support of health-authority decisions?

17:15-17:30 Concluding Remarks, Juan Marcos González Sepulveda [α] and **F. Reed Johnson** [α]

Pre-Meeting Dinner, Thursday, 6 July 2017 from 18:00 to 21:30

Les Zygomates, 129 South Street, Boston, Massachusetts, USA (1 block from Center)

Scientific Meeting, Friday, 7 July 2017 from 8:00 to 17:30

The NonProfit Center, 89 South Street, Boston, Massachusetts, USA

8:00-8:15 Arrival and Light Breakfast

8:15-8:30 Welcome and Acknowledgement of Sponsors

Meeting Chairs: **Juan Marcos González Sepulveda** [α] and **F. Reed Johnson** [α]

8:30-10:00 Session 1

But how do we know we are really measuring preferences…. A review and application of methods to assess the validity and reliability of a discrete-choice experiment**, Ellen Janssen** [β]
Can we ask people living in nursing homes to participate in a DCE?, **Rachel Milte** [β]
If you're gonna do it, do it right, right? Examining why people participate in surveys in health, **John F. P. Bridges** [α]

10:00-10:15 Mid-Morning Break

10:15-11:45 Session 2

Non-linear time preferences in health state valuations; time for time-corrected QALY tariffs? **Marcel F. Jonker** [α]
U.S. Valuation of the EQ-5D-5L, **Benjamin M. Craig** [α]
Putting Economics back into Health Economics: Welfare-Theoretic Generalized QALYs from DCE Data, **F. Reed Johnson** [α]

11:45-12:00 Elevator Talks

Establishing consensus based core outcomes in nephrology: the value of best-worst scaling surveys, **Martin Robert Howell** [β]
Who will use HIV prevention products and what might stop them? A latent class analysis, **Matthew Quaife** [α]
Preferences for an Aboriginal-specific fall-prevention program: valuing culturally-appropriate care, **Blake Angell** [β]

12:00-13:00 Lunch and Poster Session

13:00-14:30 Session 3

Empirical Tests of Best-Worst Scaling with Very Many Attributes, **Keith Chrzan** [α]
Comparing alternative opt-out formats on patient preferences for surgeon selection and waiting times, **Deborah A Marshall** [α]
A comparison of random-parameter and latent-class techniques in exploring preference heterogeneity, **Mo Zhou** [β]

14:30-14:45 Mid-Afternoon Break

14:45-16:15 Session 4

Psychiatrists' preferences in Schizophrenia treatment: Exploring individual maximum acceptable risks, **Marco Boeri**
HIV testing preferences among men who have sex men in China: a discrete choice experiment, **Stephen Warren Pan** [β]
Winning isn't everything? What else is there—reinterpreting the DCE competition winning model**, Michał Kosma Jakubczyk** [α]

16:15-16:30 Concluding Remarks

16:30-17:30 Business Session (All attendees are welcome)

[α] indicates a member presenter
[β] indicates a student presenter

IAHPR
International Academy of Health Preference Research

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About Us

Established on 15 April 2014, the International Academy of Health Preference Research (IAHPR) is a member-driven, inter-generational organization that promotes educational activities and research with respect to health and health-related preferences.

Our aim is *to improve decisions about health and healthcare throughout the world by developing, promoting, and supporting health preference research with the widest possible applicability.*

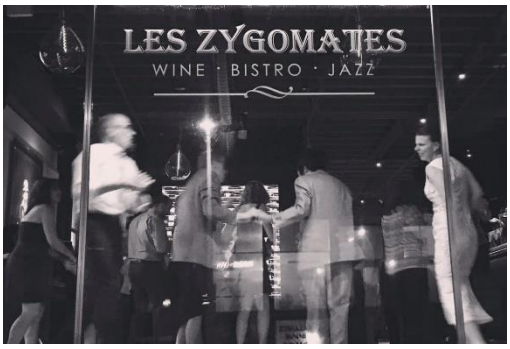
To donate to our 501(c)(3) organization, please send an email to: contact@iahpr.org

Dining Arrangement

Symposium Catering, Thursday, 6 July 2017

Upon arrival (12:30) and throughout the afternoon, coffee (regular and decaf), tea, and water as well as assorted juices and soda will be available. The buffet will start with a light snack, namely fruit skewers, homemade potato chips, and vegetable platters. During the afternoon break (14:40-15:00), mini dessert pastries will be added to the buffet.

Pre-meeting Dinner, Thursday, 6 July 2017



Les Zygomates

129 South Street
Boston, Massachusetts, USA

All attendees are invited to a **networking dinner** at Les Zygomates (1 block from the NonProfit Center). The dinner is included with registration (no guests, please).

The dinner includes:

Prosecco and Hors d'oeuvres upon arrival:
- Scallops wrapped in bacon, smoked maple
- Cheese burger sliders
- Roasted beets in fines herbes vinaigrette with goat cheese on crostini
- Savory profiteroles with wild mushroom duxelles

Charcuterie, cheese, and mezze platters, including a variety of meats, sausages, pâté, cheeses, hummus, olives, roasted peppers, grilled zucchini, tzatziki, preserved feta, pita

Dried apricot, pistachio and cucumber over mixed greens with house baked bread and butter

Leg of lamb studded with garlic and rosemary served with potato gratin

For dessert, chef's selection of assorted mini pastries

Each guest will also receive two premium bar tickets, which includes liquor mixed drinks, beers and selected wines. Non-alcoholic beverages are freely available upon request (no ticket required). If you do not use your drink tickets, you are welcome to share them with someone who will. Wines selected for this event include:

Pinot Noir - Miura, Santa Lucia Highlands, California

Cabernet Sauvignon - Hunt & Harvest, Napa Valley, California

Sauvignon Blanc - Jean Tellier, Menetou-Salon, France

Chardonnay - Patz & Hall, Russian River Valley, California

Meeting Catering, Friday, 7 July 2017

Upon arrival (7:30) and throughout the day, coffee (regular and decaf), tea, and water as well as assorted juices and soda will be available. The buffet will serve a light breakfast, namely assorted pastries, greek yogurt, and fruit salad. During the morning break (10:00-10:15), fresh fruit, nuts and New England cheeses will be added.

For lunch (12:00-13:00), the buffet have assorted sandwiches (vegetarian and non-vegetarian) and a choice of three sides: Grilled Tofu, Gingered Asparagus & Asian Eggplant with Asian Noodle; Curried Rice Salad; and Field Greens with Chickpeas & Avocado. During the afternoon break (14:30-14:45), assorted cookies, brownies, and bars will be served.

Abstracts

SESSION 1, 8:30-10:00

But how do we know we are really measuring preferences…. A review and application of methods to assess the validity and reliability of a discrete-choice experiment

Ellen Janssen, PhD, Johns Hopkins Bloomberg School of Public Health, John Bridges, PhD, Johns Hopkins Bloomberg School of Public Health

Background: Given the growing use of discrete-choice experiments (DCE) among decision makers, it is vital to demonstrate the validity and reliability of studies. Here we identify, present, and apply a variety of tests to illustrate benefits and challenges. **Methods:** 24 tests were identified as test of validity and reliability that address issues of measurement and choice theory. Of these four categories, there were eight test for measurement validity, six for measurement reliability, five for choice-theory validity, and five for choice-theory reliability. One test for each category was applied (convergent validity, test-retest, monotonicity, and scope test respectively) to illustrate these approaches. Data came from a 3-year study of treatment preferences for type 2 diabetes that conducted a pilot DCE (n = 27), a national DCE (n=552), and a national best-worst scaling case 2 (BWS) (n = 551). Tests were conducted for the national DCE. **Results:** First, convergent validity between the DCE and BWS (which had identical attributes and levels) was tested. Results from the DCE and BWS were highly correlated (Rho=91.1%). Second, test-retest stability for a repeated choice task was evaluated. Test-retest stability was higher than expected (p<0.001) with 76% of participants choosing consistently (54% expected). Third, within-set choice monotonicity was examined. 13 (3.9%) out of 337 participants that saw a dominated choice task chose the dominated treatment profile. Fourth, a scope test compared a narrowly defined nausea attribute from the national DCE to a wide nausea attribute from the pilot study. Preference estimates for the nausea attribute differed significantly (p<0.05) between the narrow and wide attribute levels, suggesting that level recoding was absent. **Conclusion**: While a variety of tests exist to assess the validity of a DCE, it remains unclear exactly when a study can be considered valid and reliable.

Can we ask people living in nursing homes to participate in a DCE?

Rachel Milte, PhD, Institute for Choice, University of South Australia, Australia, Elisabeth Huynh, PhD, Institute for Choice, University of South Australia, Australia, Julie Ratcliffe, PhD, Institute for Choice, University of South Australia, Australia, Maria Crotty, PhD, Rehabilitation, Aged and Extended Care, Flinders University, Australia

Introduction: Traditionally, people with cognitive impairment and dementia have been excluded from preference elicitation studies in health economics. The aim of this study was to investigate the preferences for psychosocial and environmental characteristics of nursing home care of people with and without cognitive impairment and to assess the impact of cognitive functioning on scale variability in a discrete choice experiment. **Methods:** Discrete choice experiment was undertaken with people living in a nursing home without or with mild or moderate cognitive impairment. Data was analysed using conditional logit models for subgroups of participants with and without cognitive impairment separately, and for the entire sample using a heteroscedastic conditional logit regression model allowing for scale heterogeneity. Swait-Louviere test was undertaken to formally test for differences in preference and scale between the two groups **Results:** 126 residents living in a nursing home completed the DCE on their own behalf, 74 (60%) without cognitive impairment while 52 (40%) participated with mild or moderate cognitive impairment. The results of the heteroscedastic conditional logit model indicated cognitive impairment as a statistically significant factor in the model (-0.403 (SE 0.188) p=0.032). The Swait-Louviere test indicated no difference in estimated coefficients between the two subgroups based on presence or absence of cognitive functioning, but evidence of a small but statistically significant difference in scale between the two groups. **Conclusions:** While the same preferences are exhibited, there is some evidence of scale variability in people with cognitive impairment living in nursing homes. Hence people with mild cognitive impairment can be considered in

preference elicitation studies but it is important to test for and take account of variability in scale. Overall the study demonstrates the potential for DCE as a valuable methodology for determining the preferences of people with mild to moderate cognitive impairment for aged care services.

If you're gonna do it, do it right, right? Examining why people participate in surveys in health

John F P Bridges, PhD, Stated-preference group, Johns Hopkins University, Ellen M Janssen, PhD, Stated-preference group, Johns Hopkins University,

Background: Patient and citizens are increasingly asked to participate in surveys about health to promote community centeredness. Ethical standards govern how one might interact with respondents, but there is a paucity of research asking what potential respondents want out of this type of research. We sought to document the preferences and motivations of potential respondents to survey research. **Methods:** Respondents from a national panel completed a discrete-choice experiment comparing pairs of potential studies respondents could participate in at a local hospital. Studies were defined across six attributes (validity, relevance, bias, burden, time, and reimbursement) with three possible levels each. A D-efficient design resulted in three blocks of 12 tasks. A choice model was estimated using a continuous coded mixed logit and latent class analysis (LCA). After completing the survey respondents were asked which motivating factors they used to justify their choices from pre-defined list of factors that were identified through community engagement. **Results:** 629 people participated in the survey. Participants valued validity (OR=2.4), relevance (OR=1.8), and minimizing bias (OR=1.7) the most. A 2-class LCA confirmed that the majority of participants (76%) valued quality indicators, but 24% of respondents strongly valued incentives such as increasing reimbursement (OR=3.4) or decreasing time (OR=1.3). While both groups had similar motivations, the quality-focused class was more likely to be motivated by "measuring real preference" ($p<0.001$) and "benefits to society" ($p=0.009$). **Conclusions:** Given the increase in studies focused on patient and community centeredness, the paucity of preference-based research focused on what patients and citizens want out of research is surprising. Understanding the motivations of respondents is not only important in designing future studies, but also in interpreting the results of existing studies.

MID-MORNING BREAK, 10:00-10:15

SESSION 2, 10:15-11:45

Non-linear time preferences in health state valuations; time for time-corrected QALY tariffs?

Marcel F. Jonker, PhD, Erasmus Choice Modelling Centre (ECMC), Elly A. Stolk, PhD, Erasmus Choice Modelling Centre (ECMC), Esther de Bekker-Grob, PhD, Erasmus Choice Modelling Centre (ECMC), Bas Donkers, PhD, Erasmus Choice Modelling Centre (ECMC)

Discrete choice experiments (DCEs) are becoming an important methodology for health state valuations. Especially the "DCE duration" format, which is designed to resemble and improve upon traditional time trade off (TTO) valuation tasks, is often used. Thus far, most investigations have imposed utility functions based on linear time preferences, which greatly simplifies the analyses. In this research, however, an efficient DCE design is used that is specifically optimized to measure non-linear time preferences. Based on 1,826 respondents from a scientific household panel, health state preferences for the Dutch SF-6D are modeled while accommodating non-linear time preferences using an exponential discounting function. When the discount rate is estimated directly, we find strong evidence of non-linear time preferences (with a discount rate of 5.5%, 95% CI = 4.9%-6.2%). Furthermore, when the discount rate is estimated as a function of health state severity, we find that living longer in better health states is less strongly discounted than living longer in more impaired health states (with a difference in the discount rate of approximately 2.5%-points). These results open-up the debate about the necessity and desirability of non-linear value sets, with potentially important implications for Health Technology Assessment calculations and regulatory decisions.

US Valuation of the EQ-5D-5L

Benjamin M. Craig, PhD, University of South Florida, Kim Rand-Hendricksen, PhD, University of Oslo and Akershus University Hospital, Norway

Background: The five-level version of the EQ-5D (EQ-5D-5L) was introduced as an improvement on the original three-level version (EQ-5D-3L). To date, six country-specific value sets have been published for EQ-5D-5L and nine U.S. value sets have been published for other instruments. The central aim of this health preference study was the valuation of the EQ-5D-5L on a quality-adjusted life year (QALY) scale from the perspective of U.S. adults. **Methods:** In 2016, 8,221 U.S. respondents from all 50 states and Washington, DC completed a brief online survey including a discrete choice experiment (DCE) with 20 paired comparisons. Each comparison asked respondents, "Which do you prefer?" regarding a pair of alternatives described using EQ-5D-5L and lifespan attributes. On the basis of more than 50 ordinal responses to 3,160 pairs, we estimated EQ-5D-5L values on a QALY scale and compared them to the U.S. EQ-5D-3L values and the other country-specific EQ-5D-5L values. **Results:** Ranging from –0.287 (55555) to 0.992 (11121) on a QALY scale, the EQ-5D-5L values were similar to the U.S. EQ-5D-3L values. Compared to the U.S. EQ-5D-3L values, the values exhibited greater sensitivity and specificity and higher correlation with the EQ-5D-5L values of other countries, particularly England. **Conclusion:** Like all U.S. valuation studies of other instruments, this study examined the preferences of U.S. adults to produce nationally representative EQ-5D-5L values on a QALY scale. The results demonstrate the advantages of the EQ-5D-5L over its three-level predecessor as a preference-based summary measure of health-related quality of life from the U.S. societal perspective.

Putting Economics back into Health Economics: Welfare-Theoretic Generalized QALYs from DCE Data

F. Reed Johnson, PhD, Duke University, Juan Marcos Gonzalez, PhD, Duke University, Meenakshi Bewtra, MD, PhD, University of Pennsylvania, Shelby Reed, PhD, Duke University

Background: Quality-adjusted life years (QALYs) are the standard metric used in health-technology assessments for changes in health-related quantity and quality of life. However, QALYs require strong, nonutility-theoretic assumptions. We derive alternative generalized healthy-time equivalents from conventional utility assumptions and illustrate their application for clinically realistic symptom and treatment durations. **Methods:** Using time instead of money for the numeraire poses challenges for deriving analogous welfare equivalents. We derive two welfare-theoretic time-equivalent analogs assuming the same and different ex ante and ex post marginal rates of substitution. We illustrate the conceptual and empirical consequences using data from a discrete-choice experiment that systematically varied health outcomes over a fixed time period to derive the required marginal rates of substitution. US adults with ulcerative colitis (UC) completed an online discrete-choice-experiment (DCE) survey with each choice question representing 3 alternatives: 2 medications and 1 surgery (J-pouch or ostomy). Treatment profiles were defined by 12-month periods allocated to time in remission and time in one of three levels of symptom severity; number of months required steroid use; and annual risks of serious infection and lymphoma due to treatment. **Results:** We obtained time-equivalent values for both health-outcome utility and non-clinical, procedural utility. For a pro-medication latent class, surgery of either kind was equivalent to a loss of 14 months of symptom-free time. For a pro-efficacy class, surgery of either kind was equivalent to 10 fewer months of symptom-free time. Pro-surgery was the only group with a statistically significant difference ($p<0.01$) between J-pouch and ostomy, with equivalent symptom-free time of 2 and 4 months, respectively. **Conclusions:** QALYs have proven useful for calibrating dissimilar health outcomes in common, intuitive time-equivalent units. It is possible to derive utility-theoretic welfare values using equivalent durations of healthy time from DCE data which avoid the restrictive assumptions of conventional QALY measures.

ELEVATOR TALKS, 11:45-12:00

Establishing consensus based core outcomes in nephrology: the value of best-worst scaling surveys

Martin Robert Howell, PhD, School of Public Health, University of Sydney, Benedicte Sautenet, PhD, University François Rabelais, Tours, France, Angela Ju, , School of Public Health University of Sydney, Andrea Viecelli, PhD, Queensland School of Medicine, University of Queensland, Germaine Wong, PhD, Centre for Transplant and Renal Research, Westmead Hospital, Kirsten Howard, PhD, School of Public Health, University of Sydney, Allison Tong, PhD, School of Public Health, University of Sydney, Jonathan C Craig, PhD, School of Public Health, University of Sydney

Background: The Standardised Outcomes in Nephrology (SONG) initiative is establishing core outcomes to be reported in clinical trials across the spectrum of kidney disease. Identifying core outcomes relies on Delphi consensus surveys with Likert rating scales that are subject to completion biases, floor/ceiling effects and provide a poor measure of preference. The aim of this study was to assess the value of inclusion of object scaling best-worst surveys (BWS). **Method:** Participants rated outcome importance on a 9 point rating scale followed by a BWS survey. Balanced incomplete block designs were used for the BWSs with participants randomly assigned to one of four blocks containing five sets of six outcomes, and asked to choose the most and least important. Preferences were estimated using a mixed multinomial logit model (MMNL) with a panel specification. **Results:** To date 1,352 (510 patients/caregivers, 842 health professionals) from 51 countries participated in three surveys (transplantation, vascular access and haemodialysis fatigue). BWS models were statistically robust with MMNL regression coefficients greater or less than 0 ($P<0.05$) for all but two of 39 outcomes. Inter-class correlation coefficients (ICC) between ratings and beta values were significant ($P<0.05$) for 26 (67%) outcomes. Due to rating scale ceiling effects, agreement was poor as the highest ICC was 0.30 (95%CI 0.22, 0.38). The fatigue survey showed evidence of cultural completion bias for rating scales for Mexican compared to English speaking respondents with mean scores of 4.1 (95%CI 3.9, 4.2) and 7.0 (95%CI 6.9, 7.1) respectively. This introduces ambiguities in interpretation of ratings. Finally, the BWS identified important differences in preferences between patient/caregivers and health professionals in all three surveys not identified by rating scales. **Conclusion:** Including a simple BWS in large international consensus surveys allows for a level of differentiation not possible with rating scales and facilitates inclusion of culturally varied groups.

Who will use HIV prevention products and what might stop them? A latent class analysis

Matthew Quaife, MSc, London School of Hygiene and Tropical Medicine, Fern Terris-Prestholt, PhD, LSHTM, Sinead Delany-Moretlwe, PhD, Wits RHI, Robyn Eakle, MSc, LSHTM, Maria de los Angeles Cabrera, MSc, Wits RHI, Peter Vickerman, DPhil, University of Bristol

Objectives: The development of antiretroviral (ARV)-based HIV prevention products has substantially changed the HIV prevention landscape, yet little is known about how appealing these products will be to potential users. Use of condoms and HIV treatment is strongly influenced by individual and structural factors, but there is not much work exploring how these might influence prevention product uptake, use, or cost-effectiveness. **Methods:** This study uses a discrete choice experiment (DCE) to explore preferences for HIV prevention products, and quantify the importance of product attributes. We analyse data from 280 South African women aged 16-25, sampled in a randomised household survey in 2015. The DCE was developed through qualitative work and literature reviews, and was extensively piloted with target populations. Respondents were asked to choose between three hypothetical products with varying attributes and an opt-out (defined as "what I did last time") over ten choice sets. A three-class latent class and mixed multinomial logit models were used to analyse choice data. **Results:** Latent class models highlight notable variations in preferences. Members of one class show strong preferences for STI and pregnancy protection, but do not value HIV protection. Structural factors, including alcohol use and exposure to violence, increase preferences for HIV protection. Despite heightened epidemiological risk among younger women, preferences for HIV protection was lower among younger women, but this group did value

contraceptive and STI protective attributes. **Discussion:** Although carried out in an area of high HIV prevalence, our results suggest that demand for new HIV prevention products may be more nuanced than simply developing highly effective products. STI and pregnancy prevention, alongside frequency of use, appears to substantially impact demand. More attention should be given to distal determinants of product demand, including social and structural vulnerabilities, to maximise impact and cost-effectiveness.

Preferences for an Aboriginal-specific fall-prevention program: valuing culturally-appropriate care

Blake Angell, BEc Soc Sci (Hons) MPH, The George Institute for Global Health, Tracey-Lea Laba, PhD, The George Institute for Global Health, Caroline Lukaszyk, BSC MIPH, The George Institute for Global Health, Julieann Coombes, BN, The George Institute for Global Health, Sandra Eades, MBBS PHD, Baker IDI, Lisa Keay, PHD, The George Institute for Global Health, Rebecca Ivers, PHD, The George Institute for Global Health, Steve Jan, PHD, The George Institute for Global Health

Background: While culturally-specific services are an integral part of efforts to improve the health of Aboriginal Australians, few published studies have empirically demonstrated the value of such services relative to mainstream alternatives. **Methods:** A discrete choice experiment (DCE) was conducted alongside a study of a culturally-specific fall-prevention service, involving choices between 2 hypothetical class options and no treatment. Attributes that were assessed were out-of-pocket costs, whether transport was provided and whether the class was Aboriginal-specific. Choices of participants were modelled using mixed logit methods. **Results:** Sixty patients completed the DCE. The cohort had an average age of 64, were 60% female and 30% of the cohort lived alone. Attending a service was strongly preferred over no service (selected 99% of the time). Assuming equivalent efficacy of fall-prevention programs, participants indicated a preference for services that were culturally-specific (OR 1.25 95% CI: 1.04-1.46) and incurred lower out of pocket participant costs (OR 1.19 95%CI 1.13-1.25). The provision of transport did not have a statistically significant influence on service choice (p=0.55). **Conclusions:** This represents the first published DCE in the health field examining preferences amongst an Aboriginal population. The results empirically demonstrate the value of the culturally-specific element of a program has to a cohort of older Aboriginal Australians and show the potential for stated preference methods and DCEs as a tool to aid in valuing culturally-specific healthcare.

LUNCH/POSTER SESSION, 12:00-13:00

SESSION 3

Empirical Tests of Best-Worst Scaling with Very Many Attributes

Keith Chrzan, BA, Philosophy of Religion, Notre Dame; MBA, Marketing, Indiana University, Sawtooth Software, Megan Peitz, MS, Mathematics and Statistics, Washington University, Sawtooth Software

Introduction: Our health preference studies routinely involve BWS models with 50+ attributes. At the same time, our clients want respondent-level utilities. Trying to accommodate large numbers of attributes while collecting enough information to produce stable respondent-level utility estimates, and doing both without fatiguing respondents requires quite a balancing act. Applied marketing researchers have devised two methods to address this complex of challenges: Express BWS and Sparse BWS. After describing the two methods, we compare them in a new empirical study. **Methods:** To address the limitations of two prior methodological studies we use a new study of 36 health preference statements disguised at the request of the study sponsor. We divided 1,200 respondents three ways - into two test cells (each containing 9 Sparse or Express BWS choice sets of quads) and a holdout cell containing a "Full" BWS experiment with 27 quads. This design allows us to compare the out-of-sample predictive validity of Express and Sparse BWS. An additional 18 BWS questions in each of the two test cells enables us to compare their ability of Sparse and Express BWS to recover respondent level parameters. **Results/Conclusions:** Sparse BWS predicts the preferences of the control cell of respondents better than does Express BWS. Correlations of mean vectors

of Sparse BWS and holdout BWS utilities is 0.96, compared to 0.90 for Express BWS with the holdouts ($t = 3.339$, $p < 0.001$). Similar results occur for predictions of ranks ($t = 2.338$, $p = 0.008$). Sparse again outperforms Express BWS in its ability reproduce the utilities of individual respondents completing the Full 27-set BWS experiment. Correlation of Sparse with Full BWS at the respondent level is 0.80 while for Express and Full it is only 0,61. The t statistic 35.47 is wildly significant, at $p < 0.001$.

Comparing alternative opt-out formats on patient preferences for surgeon selection and waiting times

Deborah A Marshall, PhD, University of Calgary, Ken Deal, PhD, McMaster University, Barbara Conner-Spady, PhD, University of Calgary, Eric Bohm, MD, MSc, University of Manitoba, Gillian Hawker, MD, MSc, University of Toronto, Lynda Loucks, MSc, Concordia Hip and Knee Institute, Dean A Regier, PhD, University of British Columbia, Claudia Sanmartin, PhD, Statistics Canada, Karen V MacDonald, MPH, University of Calgary, Tom Noseworthy, MD, MSc, MPH, University of Calgary

INTRODUCTION: Discrete choice experiment (DCE) choice tasks should reflect choices that are plausible to the extent possible. In health, the option to choose none of the alternatives (opt-out) is important to capture. Previous research has explored the impact of including opt-out, but there is limited research comparing alternative opt-out formats. We compared 2 different choice task and opt-out formats for a reference scenario that represented the 'common current scenario' to determine if the utility of the attributes and levels is different between the 2 formats. **METHODS:** We mailed a questionnaire, including a 12 choice task DCE, to 1000 patients referred as candidates for total joint replacement (TJR) surgery. Five attributes were defined based on previous research, pre-testing and pilot testing: surgeon reputation, surgeon selection process, waiting time to surgeon visit, waiting time to surgery and travel time to hospital. The experimental design included 8 versions of the DCE that were administered in consecutive order, alternating between formats: 4 versions used a 2 scenario choice task plus the 'common current scenario' as one of three alternative choices, and 4 versions used a 2 scenario choice task with the 'common current scenario' presented as a follow up opt-out option. Preferences were estimated using hierarchical Bayes analysis and evaluated for goodness-of-fit. **RESULTS:** Of 422 participants, 59% were female, 68% were referred for knee TJR, and measures of pain and physical function were typical of patients referred as TJR candidates. The most important attribute was surgeon reputation followed by waiting time to surgery. Patients appear willing to wait 10 months for consultation with an excellent reputation surgeon before switching to a good reputation surgeon. There were no statistically significant differences between the two opt-out formats. **CONCLUSIONS:** At least in this sample, the two opt-out formats for the reference scenario generated similar preference weights.

A comparison of random-parameter and latent-class techniques in exploring preference heterogeneity

Mo Zhou, PhD, MPA, Johns Hopkins Bloomberg School of Public Health, John FP Bridges, PhD, Johns Hopkins Bloomberg School of Public Health

There has been an increasing interest in studying patient preference heterogeneity to support regulatory decision-making. While the traditional mixed logit (MXL) and latent class logit (LCL) models have been commonly used to analyze preference heterogeneity in discrete choice data, they have limitations. For example, LCL often leads to too many classes when there is substantial within-class preference heterogeneity or significant overlap between classes. As MXL can accommodate more extensive heterogeneity with fewer parameters, it may not be sufficient when there are sizeable subgroups. This study empirically compares an innovative random effect latent class logit (RELCL) model to the traditional approaches using preference data from a discrete-choice experiment among patients with type II diabetes. The survey contained 18 pairs of hypothetical diabetes medications that differed in six attributes. Significant preference heterogeneity was found in all models. The best-fitted RELCL has the lowest BIC (8350.64) and predication error (11.61%) compared to MXL (BIC=8587.38; pred. err.=13.02%) and the best-fitted scale-adjusted LCL (BIC=8403.18; pred. err.=15.69%), indicating improved model fit. Allowing random effect also

reduces the number of classes from five in scale-adjusted LCL to two and both have significant policy and clinical implications. RELCL provides the flexibility of LCL and the parsimony of MXL. When significant within-class heterogeneity exists as in patients with prevalent chronic diseases, RELCL may be used to generate more accurate predictions and more parsimonious results that are policy-relevant.

MID-AFTERNOON BREAK, 14:30-14:45

SESSION 4

Psychiatrists' preferences in Schizophrenia treatment: Exploring individual maximum acceptable risks

Marco Boeri, PhD, Health Preference Assessment, RTI Health Solutions, NC, USA, Alan J McMichael AJ, PhD, Queen's university Belfast, Francis O'Neill, PhD, Queen's University belfast, Joseph PM Kane, PhD, New castle university, Frank Kee, PhD, Queen's University Belfast

Prescribing a treatment with risks that patients are not willing to tolerate results in poor adherence and outcomes. In this context, discrete choice experiments (DCEs) have been widely employed in health preference assessment to investigate how respondents trade off risks and benefits by deriving the maximum acceptable risk (MAR). Many studies explored differences between patients and physicians finding that in some instances they are aligned and in some, they are not. However, it is also important to understand whether there is variation across clinicians as this might result in unacceptable outcome variations and inequities in care. This study aims to explore the extent of MAR heterogeneity across a sample of clinicians (psychiatrists) when prescribing drugs for schizophrenic patients, observed in a series of 26 Choice tasks (or vignettes). We estimated a random parameter logit (RPL) model to analyze the data. Using the mean estimate for benefit (symptom control) and risk of the treatment (probability of 10kg weight gain), we firstly computed an average MAR of about 4%, implying that, overall, psychiatrists were willing to accept a 4% increase in the risk of side effect to obtain a one unit decrease in symptom score. However, results are richer when we fully utilize the sequence of choices, whereby it is possible to retrieve individual posterior conditional parameters for each clinician using Bayes theorem, as described in the paper. We find that physicians have an individual MAR that ranges between 0.5 and 9.5 The study aimed to show how to calculate individual specific MAR and the results could have some important clinical practical implications. In some contexts, there may be good reasons for understanding why MAR may vary across clinicians and, if personalized medicine gains traction, future research should focus on understanding how they might relate to individual MAR.

HIV testing preferences among men who have sex men in China: a discrete choice experiment

Stephen Warren Pan, PhD, University of North Carolina at Chapel Hill, Maya Durvasula, BA (candidate), Duke University, Chuncheng Liu, BA, UNC - Project China, Jason Ong, MD, PhD, UNC - Project China, Weiming Tang, PhD, University of North Carolina at Chapel Hill, Joseph David Tucker, MD, PhD, University of North Carolina at Chapel Hill, Fern Terris-Prestholt, PhD, London School of Hygiene and Tropical Medicine

Background: In China, men who have sex with men (MSM) are a stigmatized social group with low HIV test uptake, potentially because available services may not match MSM testing preferences. We used a discrete choice experiment (DCE) to elicit HIV testing preferences of MSM in China. **Methods:** The DCE was conducted in three stages from June 2016 to January 2017. Stage one: focus groups with 24 self-identified Chinese MSM were conducted to identify test attributes and levels that influence HIV testing decisions. Stage two: an unlabeled DCE design was generated in NGENE. MSM over age 16 were recruited via online dating platforms throughout China to complete a pilot DCE (n=96). Participants were given six choice sets, each of which asked them to choose between two hypothetical HIV testing scenarios and a "do not test" alternative. Stage three: pilot study results were used to parameterize a d-efficient design for a nationwide

DCE. Effects coding and the MLOGIT package in R (RPL model) were used to calculate parameter estimates. All design attributes were set as random with normal distributions. Two-way interactions were created by crossing design attributes with sociodemographic characteristics. **Results:** 803 participants completed 4738 choice tasks. In 8% of choice tasks, participants chose the "opt-out" (do not test) alternative. Participants preferred anonymous testing (β=0.33, SE=0.04), not to disclose MSM activities (β=0.13, SE=0.03), incentivized testing (~$7.50 USD) (β=0.31, SE=0.05), and free testing (β=0.49, SE=0.06). Participants who did not identify as gay had a stronger preference for anonymous testing (β=0.19, SE=0.08). Individuals with lower income were more responsive to testing incentives (β=0.09, SE=0.04) and fee-based testing (β=-0.11, SE=0.04). **Conclusion:** Online dating platforms are an efficient means of reaching non-gay identifying MSM. To increase HIV testing among Chinese MSM, policy makers should offer free, anonymous testing that does not require disclosure of MSM activities.

Winning isn't everything? What else is there—reinterpreting the DCE competition winning model

Michał Kosma Jakubczyk, PhD, SGH Warsaw School of Economics

Background: DCE competition promoted predictive validity as model-evaluation criterion. Still, health preference experiments are typically not conducted to subsequently predict people's choices, but to understand preferences and support decisions, preferably by assigning utilities to health states. The scoring function used by the competition winning model is not easily interpreted. I propose a method to reinterpret it and to derive value sets and infer about preferences. **Approach:** Using the scoring function, I simulate a time trade-off (TTO) experiment: for state, Q, we find time, T, such that 10 years in Q or T years in full health would each be chosen with 50% probability; thus, u(Q)=T/10. The simulation fails for severe states (for T too close to zero for a standard TTO) and disallows lead-time TTO; hence, I extrapolate the available results with linear regression. For comparison, I simulate a modified version with different time spent in Q: 12 months/10 weeks/30 days (used in competition in TTO pairs) or 5/20 years (not used). **Results:** The basic simulation results in the regression model with intercept=0.013 and the following level-5 dimension disutilities: mobility, MO=0.424; self-care, SC=0.516; usual activities, UA=0.368; pain/discomfort, PD=0.584; anxiety/depression, AD=0.488. The predicted utility of pit state is very low: u(55555)=-1.4. The level 2–4 multiplier is same across the dimensions: 0.095, 0.217, and 0.798, respectively. The results differ, e.g., for TTO using 30-days-in-Q: intercept=0.107, MO=0.571, SC=0.584, UA=0.436, PD=0.752, and AD=0.642; yielding lower utilities in the value set. Relative importance of SC and UA decreases: short-term problems in these dimension are more easily accepted. Levels multipliers do not change. Results change more substantially for 5/20 years simulations. **Conclusions:** Value sets can be inferred indirectly, also from models with complicated scoring functions. Preferences towards health states change non-trivially with hypothetical state duration. The discussion about the importance of predictive validity should continue.

CONCLUDING REMARKS, 16:15-16:30

BUSINESS SESSION, 16:30-17:30

Agenda for the Business Session

Opening, Juan Marcos González Sepulveda and F. Reed Johnson

Science, Derek S. Brown, Scientific Director

- Abstract Review Process
- Upcoming Meetings and Symposia

Publications, Benjamin M. Craig, Chair

- Papers
- Journal
- Textbook

Development, Axel C. Mühlbacher, Vice Chair

- Health Preference Study and Technology Registry
- Certification Program

Discussion on sustainability, Juan Marcos González Sepulveda and F. Reed Johnson

Closing, Juan Marcos González Sepulveda and F. Reed Johnson

Note: The Academy encourages all attendees to participate in the business session. Like presentations, meeting participation is a practical indicator of service to the Academy and demonstrates a commitment to the Academy's mission and the field. Attendance is taken during the business session, because non-attendance for 2 years can trigger IAHPR membership to lapse.

FDA Research Fellow Position

ORISE Fellow, 12 months, extendable
FDA Center for Devices and Radiological Health

Project Description:

The FDA values the experience and perspectives of patients, and understands that patients and care-partners who live with a disease or condition on a daily basis may have developed their own insights into and perspectives on the benefits and risks of devices reviewed by the FDA. Recent FDA guidance encourages submission of patient preference information to aid in FDA decision making, and the FDA is conducting patient preference studies to support FDA decision making in preference-sensitive areas. The research fellow would train in the development, conduct, and dissemination of a patient preference study to support medical device benefit-risk assessment.

Qualifications:

- Experience in one or more of the following areas:
  - Patient preferences
  - Patient-reported outcome measures
  - Biostatistics, epidemiology
  - Health economics, behavioral economics
  - Qualitative research
  - Patient interaction, patient engagement, or patient input
  - Clinical trial design
- Graduate degree in related field
- Excellent written and oral communication

Activities:

- Conduct literature review on clinical outcomes of medical devices
- Liaise with regulatory reviewers and medical officers to inform development of patient preference study
- Develop interview or focus group protocols for identifying outcomes of importance to patients, family, and caregivers
- Coordinate and/or conduct interviews, focus groups with patients, family, and caregivers
- Design a patient preference survey
- Analyze patient preference data obtained from the survey
- Prepare data and models for public dissemination and peer-reviewed manuscript

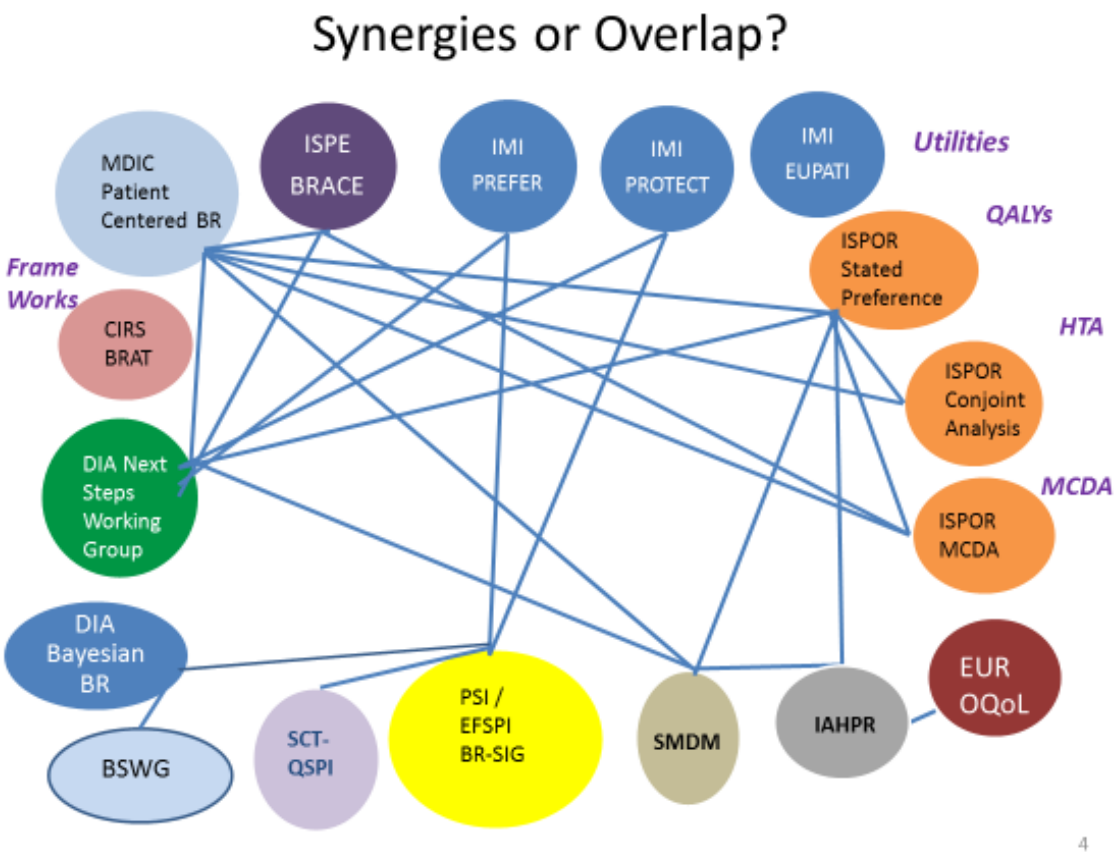
Contact: mdfp@fda.hhs.gov

U.S. Food & Drug Administration
10903 New Hampshire Avenue
Silver Spring, MD 20993
www.fda.gov

20 June 2017

Survey of Benefit-Risk Groups and Organizations

Mike Colopy, PhD, Global Statistical Sciences, UCB Biosciences



Survey Responders

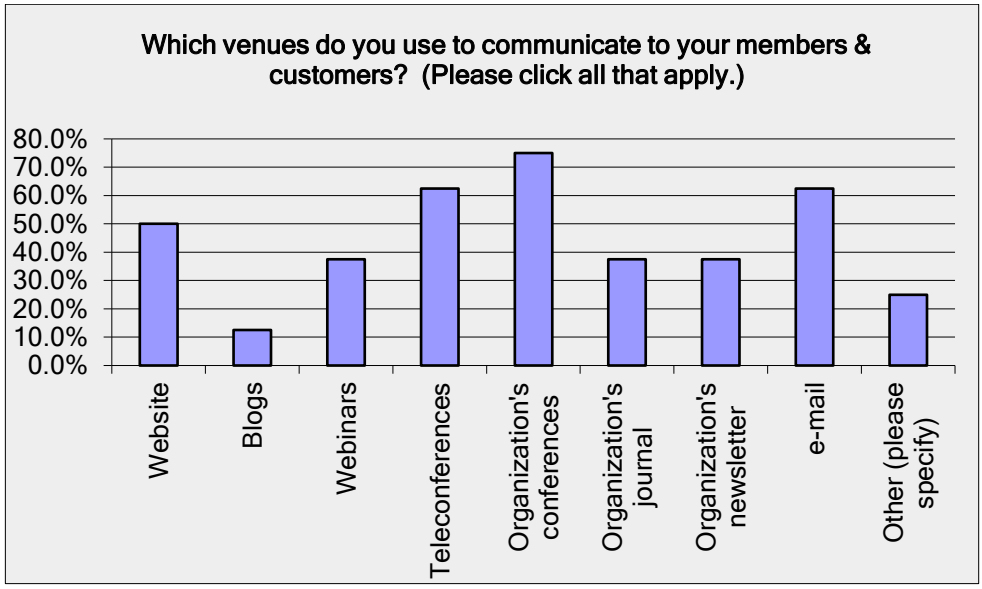
1.DIA Next Steps Working Group
  ISPE BRACE (Intl. Soc. Pharmacoepidemiology BR Assessment, Communication & Evaluation)
  IMI PREFER (Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle)
  IMI PROTECT (Pharmacoepidemiological Research Outcomes Therapeutics European Consortium)
2.DIA Bayesian Scientific Working Group Benefit-Risk Subteam - ADSWG Expedited Approvals
3.International Academy of Health Preference Research
4.ISPOR Stated Preference SIG (Intl. Soc. Pharmacoeconomics & Outcomes Research)
5.MDIC Patient Centered BR Group (Medical Device Innovation Consortium)
6.PSI / EFSPI BR SIG (European Federation of Statisticians in Pharm. Industry)
7.SCT-QSPI (Soc. Clinical Trials - Quantitative Sciences in Pharm. Industry)

This survey collected responses from multiple persons involved in BR Groups and Organizations. Some groups (above) have disbanded after completing their deliverables: IMI PROTECT and EUPATI and ISPOR Conjoint Analysis and MCDA SIGs. The survey did not receive responses from EuroQol Group or CIRS BR Task Force (Center for Innovation I Regulatory Science); otherwise, this list appears complete and up-to-date. This report presents frequency tables and the survey responses. If resources are available, this survey will be repeated in 2018.

The organizations are evenly split between inviting new members, being open to anyone interested and requiring new applicants to meet entry requirements.

Who can be a member?	
Answer Options	**Response Count**
Open to all comers	2
Open to members of parent organization	0
Open to those who meet entry requirements	2
By invitation only	2
Other (please specify)	1
answered question	**7**
skipped question	**1**

The most popular venue for communication are conferences, followed by teleconferences. Blogs (see EFSPI) are far less common.



Even though a few of the organizations focus on stated preference, all organizations support sponsor and regulatory decision-making.

Which of the following "decision-making" activities does your BR group support? (Please click all that apply.)		
Answer Options	**Response Percent**	**Response Count**
Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.)	100.0%	8
Sponsor's post-approval decisions	87.5%	7
Regulatory decisions	100.0%	8
Patient decisions	50.0%	4
Practitioner decisions	62.5%	5
HTA / payer decisions	62.5%	5
Other (please specify)		1
answered question		**8**
skipped question		**0**

It is not surprising that most groups advance decision frameworks. An equal percentage advance regulatory acceptance and guidance and decision sciences. Risk communications and risk mitigation is probably only supported by ISPE BRACE. Software is least supported. It is worth noting that AstraZenecca is developing its own BRAT-like software (demo'd at a NSWG meeting).

Which of the following areas does your BR group advance? (Please click all that apply.)		
Answer Options	**Response Percent**	**Response Count**
Training & Education	50.0%	4
Consulting	25.0%	2
Frameworks	75.0%	6
Patient advocacy or participation	25.0%	2
Regulatory acceptance & guidance	75.0%	6
Risk Communications	25.0%	2
Risk Mitigation	0.0%	0
Decision sciences	75.0%	6
Quantitative methods	100.0%	8
Software	12.5%	1
Other (please specify)		0
answered question		**8**
skipped question		**0**

The most popular methodologies being developed are quantitative trade-offs, followed by weighting & scoring and uncertainty & variability. Lesser served topics are indexes, incorporating elements of time and indirect comparisons.

Which of the following methodologies does your BR group research & develop? (Please click all that apply.)		
Answer Options	**Response Percent**	**Response Count**
Visualization	62.5%	5
Integration of disparate data sources	37.5%	3
Conversion to common units	50.0%	4
New metrics	37.5%	3
Uncertainty & variability	75.0%	6
Weighting & scoring	75.0%	6
Thresholds	50.0%	4
Indexes	25.0%	2
Utilities	50.0%	4
Quantitative trade-offs	87.5%	7
Estimation	37.5%	3
Incorporating element of time	25.0%	2
Indirect comparisons (ex. network meta-analysis)	25.0%	2
Bayesian approaches	62.5%	5
Statistical modeling	62.5%	5
Decision theory	50.0%	4
Other (please specify)		1
answered question		**8**
skipped question		**0**

DIA Next Steps Working Group; ISPE BRACE; IMI PREFER; IMI PROTECT;

Who is the current leader and/or primary contact for your BR group? Becky Noel, DrPH, MSPH, I have represented CIRS & IMI PROTECT and now represent DIA NSWG, IMI PREFER & ISPE BRACE
Please enter your contact information (e.g. e-mail address) noelrn@lilly.com
What year was your BR group established? NSWG/DIA 2010; IMI PROTECT (completed); BRACE 2013; IMI PREFER 2016
Approximately, how many members are in your BR group?
Who can be a member?
Who makes up your core membership? A mix of professionals representing Epidemiology, Economics, HTA, Regulatory Agencies, Academics, Statistics & other quantitative scientists
Who is your primary customer?
Please state the primary goals, focus & deliverables of your BR group. Development and use of structured benefit-risk assessment and visualizations; Development and optimal use of patient preferences in benefit-risk decision-making
Which venues do you use to communicate to your members & customers? Website, Webinars, Teleconferences and Organization's conferences
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc.

- http://www.imi-prefer.eu/
- http://www.imi-protect.eu/

Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, HTA / payer decisions
Which of the following areas does your BR group advance? Frameworks, Regulatory acceptance & guidance, Quantitative methods
Which of the following methodologies does your BR group research & develop? Visualization, Integration of disparate data sources, Uncertainty & variability, Weighting & scoring, Quantitative trade-offs, Indirect comparisons (ex. network meta-analysis), Bayesian approaches, and Statistical modeling
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? DIA Next Steps Working Group, IMI PROTECT (Pharmacoepidemiological Research Outcomes Therapeutics European Consortium), IMI PREFER (Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle), ISPE BRACE (Intl. Soc. Pharmacoepidemiology BR Assessment, Communication & Evaluation), MDIC Patient Centered BR Group (Medical Device Innovation Consortium), and Society for Medical Decision Making
Is there any other information about your group that you would like to share?

DIA Bayesian Scientific Working Group – Benefit-Risk Subteam (ADSWG Expedited Approvals)

Who is the current leader and/or primary contact for your BR group? Zoran Antonijevic, Larry Gould, Bob Campbell
Please enter your contact information (e.g. e-mail address) zorana@amgen.com
What year was your BR group established? 2016
Approximately, how many members are in your BR group? 15
Who can be a member? Open to all comers
Who makes up your core membership? Statisticians & other quantitative scientists, Regulatory people and Academics
Who is your primary customer? Pharmaceutical industry

Please state the primary goals, focus & deliverables of your BR group. Assess impacts of expedited approvals
Which venues do you use to communicate to your members & customers? Teleconferences. Other venues under development
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc. NA
Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, Patient decisions, Practitioner decisions, and HTA / payer decisions
Which of the following areas does your BR group advance? Regulatory acceptance & guidance, Risk Communications, Decision sciences, and Quantitative methods
Which of the following methodologies does your BR group research & develop? Utilities, Bayesian approaches, Statistical modeling, and Decision theory
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? DIA Bayesian Scientific Working Group Benefit-Risk Subteam
Is there any other information about your group that you would like to share?

International Academy of Health Preference Research (IAHPR)

Who is the current leader and/or primary contact for your BR group? Benjamin M. Craig, PhD
Please enter your contact information (e.g. e-mail address) contact@iahpr.org
What year was your BR group established? 2014
Approximately, how many members are in your BR group? As of 2017, 36 tenured members, 18 tenure track members, and 15 student members.
Who can be a member? To become a member, a person must give a presentation at an Academy meeting. The concept is that membership is about service.
Who makes up your core membership? Health preference researchers from academia, government, non-profits, contract-research organizations, and industry, including a mix of Econometricians, Statisticians & other quantitative scientists, Regulatory people, Healthcare practitioners, HTA people, and Academics.
Who is your primary customer? All of the above as well as students
Please state the primary goals, focus & deliverables of your BR group. Our bylaws state that the primary purpose of the Academy is "to perform and promote educational activities and scientific research with respect to health and health-related preferences"
Which venues do you use to communicate to your members & customers? Website, Webinars, Teleconferences, Organization's conferences, Organization's newsletter, and e-mail
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc.

- https://www.iahpr.org (Academy's website)
- https://www.hpstr.org (Health Preference Study and Technology Registry)

Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, Patient decisions, Practitioner decisions, HTA / payer decisions, See meeting programs...
Which of the following areas does your BR group advance? Training & Education, Consulting, Frameworks, Regulatory acceptance & guidance, Decision sciences, Quantitative methods, and Software
Which of the following methodologies does your BR group research & develop? Visualization, Integration of disparate data sources, Conversion to common units, New metrics, Uncertainty & variability, Weighting & scoring, Thresholds, Indexes, Utilities, Quantitative trade-offs, Estimation, Incorporating element of time,

Indirect comparisons (ex. network meta-analysis), Bayesian approaches, Statistical modeling, and Decision theory. (See meeting programs)
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? Society for Medical Decision Making and EuroQol Group
Is there any other information about your group that you would like to share? On March 1, 2017, we launched the Health Preference Study and Technology Registry (HPSTR.org). This will allows the registration of studies and technologies (e.g., decision aids, QALYs) for use in regulatory and other decisions. It will also list all active scientists in the field (i.e., active, registered protocols) and promote quality.

ISPOR Stated-Preference Methods SIG

Who is the current leader and/or primary contact for your BR group? SIG has no leadership. Within SIG, Stated Preference Research in the European Union Working Group led by Axel Mühlbacher, PhD and Kevin Marsh, PhD
Please enter your contact information (e.g. e-mail address)
What year was your BR group established? 2010
Approximately, how many members are in your BR group? 50
Who can be a member? Open to all comers
Who makes up your core membership? A mix of professionals representing Economics, HTA, Epidemiology, Regulatory Agencies, Academics, Statistics & other quantitative scientists
Who is your primary customer?
Our group's members
Please state the primary goals, focus & deliverables of your BR group. Development of methods, opportunities for presentations, influence regulatory developments
Which venues do you use to communicate to your members & customers? Organization's conferences and e-mail
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc. ISPOR U.S. and European annual conferences
Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, Patient decisions, and Practitioner decisions
Which of the following areas does your BR group advance? Training & Education, Frameworks, Patient advocacy or participation, Regulatory acceptance & guidance, Decision sciences, and Quantitative methods
Which of the following methodologies does your BR group research & develop? Visualization, Conversion to common units, New metrics, Uncertainty & variability, Weighting & scoring, Thresholds, Indexes, Utilities, Quantitative trade-offs, Estimation, Incorporating element of time, Statistical modeling, and Decision theory
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? DIA Next Steps Working Group, International Academy of Health Preference Research, ISPOR Conjoint Analysis Task Force, and Society for Medical Decision Making
Is there any other information about your group that you would like to share?

MDIC Patient Centered BR Group (Medical Device Innovation Consortium)

Who is the current leader and/or primary contact for your BR group? Bennett Levitan
Please enter your contact information (e.g. e-mail address)
What year was your BR group established? 2013
Approximately, how many members are in your BR group?
Who can be a member? Open to those who meet entry requirements
Who makes up your core membership? Industry and FDA
Who is your primary customer?
Please state the primary goals, focus & deliverables of your BR group.
Which venues do you use to communicate to your members & customers? Teleconferences and e-mail
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc.
https://www.mdic.org/pcbr
Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Regulatory decisions
Which of the following areas does your BR group advance? Frameworks and Quantitative methods
Which of the following methodologies does your BR group research & develop? Thresholds, Utilities and Quantitative trade-offs
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Maybe
Which of these BR groups do you already communicate with or have joint activities? ISPE BRACE (Intl. Soc. Pharmacoepidemiology BR Assessment, Communication & Evaluation), ISPOR Stated Preference SIG (Intl. Soc. Pharmacoeconomics & Outcomes Research), ISPOR Conjoint Analysis Task Force, ISPOR Multi-Criteria Decision Analysis Task Force, and Society for Medical Decision Making
Is there any other information about your group that you would like to share?

PSI / European Federation of Statisticians in Pharmaceutical Industry BR SIG

Who is the current leader and/or primary contact for your BR group? Alexander Schacht
Please enter your contact information (e.g. e-mail address) schacht_alexander@lilly.com
What year was your BR group established? 2012
Approximately, how many members are in your BR group? 25
Who can be a member? Open to those who meet entry requirements
Who makes up your core membership? Statisticians & other quantitative scientists
Who is your primary customer? Our parent organization
Please state the primary goals, focus & deliverables of your BR group. The main aims of the SIG are: • To understand how best to apply Benefit-Risk Methodologies across the Pharmaceutical Industry • To discuss and make recommendations on key methodological issues • To share examples of how Benefit-Risk has been used within pharmaceutical companies • To share external information including new developments around Benefit-Risk See more at: http://www.psiweb.org/about-us/sigs-special-interest-groups/benefit-risk-sig#sthash.WvStpyrV.dpuf
Which venues do you use to communicate to your members & customers? Website, Blogs, Webinars, Organization's conferences, Organization's journal and e-mail
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc.

- http://www.benefit-risk-assessment.com/
- http://www.psiweb.org/about-us/sigs-special-interest-groups/benefit-risk-sig
- QSPI & EFSPI B-R Newsletter

Which of the following "decision-making" activities does your BR group support?

Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, and HTA / payer decisions
Which of the following areas does your BR group advance? Training & Education, Patient advocacy or participation, Risk Communications, Decision sciences, and Quantitative methods
Which of the following methodologies does your BR group research & develop? Visualization, Uncertainty & variability, Weighting & scoring, Quantitative trade-offs, Estimation, and Bayesian approaches
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? IMI PROTECT (Pharmacoepidemiological Research Outcomes Therapeutics European Consortium), IMI PREFER (Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle), and SCT-QSPI (Soc. Clinical Trials - Quantitative Sciences in Pharm. Industry)
Is there any other information about your group that you would like to share?

Society for Clinical Trials-QSPI Benefit-Risk Working Group

Who is the current leader and/or primary contact for your BR group? Qi Jiang and Weili He
Please enter your contact information (e.g. e-mail address) weili.he@abbvie.com
What year was your BR group established? 2012
Approximately, how many members are in your BR group? 15
Who can be a member? By invitation only
Who makes up your core membership? Statisticians & other quantitative scientists, Regulatory people and Academics
Who is your primary customer? Pharmaceutical industry
Please state the primary goals, focus & deliverables of your BR group. Prepare statisticians for increased use of BRA approaches through training/education Educate broader statistical community to understand this important area and to increase the role of statistical leadership through cross-functional collaboration Where appropriate, develop new methods to address the existing BRA challenges and/or provide relevant clinical contexts and guidance on the use of existing BRA methods Work with regulatory agencies to promote structured BRA.
Which venues do you use to communicate to your members & customers? Teleconferences, Organization's conferences, Organization's journal, Organization's newsletter and e-mail
Please provide titles of your organization's websites, blogs, conferences, newsletters, journals, etc.
Which of the following "decision-making" activities does your BR group support? Sponsor's pre-approval decisions (ex. CDPs, TPPS, Go-No-Go decisions, DMCs, trial designs, etc.), Sponsor's post-approval decisions, Regulatory decisions, and Practitioner decisions
Which of the following areas does your BR group advance? Training & Education, Consulting, Frameworks, Regulatory acceptance & guidance, Decision sciences, and Quantitative methods
Which of the following methodologies does your BR group research & develop? Visualization, Integration of disparate data sources, Conversion to common units, New metrics, Uncertainty & variability, Weighting & scoring, Thresholds, Quantitative trade-offs, Bayesian approaches, and Statistical modeling
Would you be interested in participating in a panel discussion between BR group leaders, to foster inter-group communications? Yes
Which of these BR groups do you already communicate with or have joint activities? PSI / EFPSI BR SIG (European Federation of Statisticians in Pharm. Industry)
Is there any other information about your group that you would like to share?

Future Meetings

Our next meeting will be in Glasgow, Scotland on **3-4 November 2017**, and chaired by **Karin Groothuis-Oudshoorn** and **Terry Flynn**. Its pre-meeting symposium will be on "*The Econometrics of Preference Heterogeneity*." Abstracts are due by **8 August** and early registration closes **17 September**.

8th Meeting of the International Academy of Health Preference Research
September 2018, chaired by **Brendan Mulhern** and **Richard Norman**
Afternoon symposium on "*Design of Discrete Choice Experiments*" followed by scientific meeting
TBD, Australia

9th Meeting of the International Academy of Health Preference Research
13-14 October 2018, chaired by **Meenakshi Bewtra** and **Jan Ostermann**
Scientific meeting followed by morning symposium on "*Support Tools for Preference-Sensitive Decisions*"
Centre Monte-Royal, Montréal, Québec, Canada

10th Meeting of the International Academy of Health Preference Research
13-14 July 2019, chaired by **Esther W. de Bekker-Grob** and **Jennifer A. Whitty**
Basel, Switzerland or Freiburg, Germany

11th Meeting of the International Academy of Health Preference Research
November 2019, chaired by two very smart people
TBD, Auckland, New Zealand

For more information, visit iahpr.org.

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