The 9th Meeting of the International Academy of Health Preference Research

Scientific Meeting
Saturday, 13 October 2018
from 08:00 to 17:30

Networking Dinner
Saturday, 13 October 2018
from 18:00 to 22:00

Symposium
Sunday, 14 October 2018
from 8:00 to 12:00

Chaired by **Meenakshi Bewtra, MD, MPH** and **Jan Ostermann, PhD**, this full-day meeting and half-day symposium in Montréal, Québec, Canada will provide a forum to present and discuss innovative developments in health preference research. The **Scientific Meeting** will include peer-reviewed podium presentations, lunch, and a business session followed by a networking dinner.

The **Symposium** will focus on "**Support Tools for Preference-Sensitive Decisions**" and include a panel discussion on developing and integrating such tools in clinical practice. Both the meeting and symposium will be held at the Centre Mont-Royal (right).

Centre Mont-Royal
2200 Mansfield Street,
Montréal, Québec H3A 3R8 Canada

Decca77
1077 Rue Drummond
Montréal, Québec H3B 4X4 Canada

All registered attendees are invited to attend the **networking dinner** at the Decca 77 (13-minute walk from Centre Mont-Royal; left). At this dinner in the Mezzanine, attendees will be served a multi-course menu and given two drink-tickets per person. This dinner is included with registration for either the symposium, meeting or both (no guests, please).

For more information, visit www.iahpr.org or email contact@iahpr.org

PROGRAM

Scientific Meeting, Saturday, 13 October 2018 from 08:00 to 17:30

Centre Mont-Royal, 2200 Mansfield Street, Montréal, Québec H3A 3R8 Canada

8:00-8:15 **Arrival and Light Breakfast**

8:15-8:45 **Welcome and Acknowledgement of Sponsors**
Meeting Chairs: **Meenakshi Bewtra**[α] and **Jan Ostermann**[α]

8:45-10:15 **Session 1**

Deriving a Clinical Preference-Diagnostic Procedure from Large-Sample Choice-Experiment Data, **F. Reed Johnson**[α]
Adjusting for Scale Confounds in Preference-Sensitive Decisions: Does it Work? **Jay Magidson**
Development and evaluation of an individualized decision aid for atrial fibrillation, **Nick Bansback**

10:15-10:30 **Coffee Break**

10:30-12:00 **Session 2**

Dominance in Stated Choice Experiments: Scary Monster, Annoyance, or Nothing Burger? **Keith Chrzan**[α]
Risky Business: Benefit-Risk Tradeoff Measures for Concurrent Risks, **Angelyn Otteson Fairchild**
From a different angle: a novel approach to modeling health preferences, **John D. Hartman**[α]

12:00-13:00 **Lunch**

13:00-14:30 **Session 3**

How common and how useful are debriefing questions in health economics DCEs? **Alison Pearce**
Internal-validity checks in a stated-preference study: implications on preferences & valid responses, **Rachael L. DiSantostefano**
Comparison of three contingent valuation techniques: The case of ovulation induction in Quebec, **Thomas G. Poder**[α]

14:30-14:45 **Coffee Break**

14:45-16:15 **Session 4**

Women's Health: Do patients with advanced breast cancer care about TTP independent of OS? **Axel C. Mühlbacher**[α]
What Australian gay and bisexual men want from HIV self-test kits: a discrete choice experiment, **Jason Ong**
Patients' and Caretakers' Treatment Preferences in the End-of-Life Setting, **Aaron B. Cohen**

16:15-16:30 **Concluding Remarks**

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

Meeting Dinner, Saturday, 13 October 2018 from 18:00 to 22:00

Decca77, 1077 Rue Drummond, Montréal, Québec H3B 4X4 Canada

Symposium, Sunday, 14 October 2018 from 8:00 to 12:00

Centre Mont-Royal, 2200 Mansfield Street, Montréal, Québec H3A 3R8 Canada

8:00-8:10 **Welcome and Acknowledgement of Sponsors**
Meeting Chairs: **Meenakshi Bewtra**[α] and **Jan Ostermann**[α]

8:10-9:40 **Session 1 – Introduction**[α]

Supporting preference-sensitive decisions: Key steps to developing tools, **Janine van Til**[α]
Using individualized patient-reported outcomes and preferences in medical decision making - a patient decision aid for patients considering total knee arthroplasty, **Deborah A. Marshall**[α]
Incentivizing clinicians to consider patient preferences, **Nick Bansback**

9:40-10:00 **Coffee Break**

10:00-11:00 **Session 2 – Two Case Studies**

Training home care teams to support informed value-congruent decisions of older adults and their caregivers, **France Légaré**
What can we do for you today? BEACON PROQOL System for case management, **Jeff Sloan**

11:00-12:00 **Session 3 – Panel Discussion on "Support Tools for Preference-Sensitive Decisions"**

11:45-12:00 **Concluding Remarks**

[α] indicates a IAHPR member

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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

Meeting and Symposium Catering

Centre Mont-Royal

2200 Mansfield Street, Montréal, Québec
H3A 3R8 Canada

Upon arrival (7:30) and throughout the afternoon, coffee (regular and decaf), tea, and water as well as assorted juices and soda will be available. Each day starts with a **light continental breakfast** including: assorted miniature viennoiseries, breads and bagels to be toasted, butter, cream cheese and preserves.

Morning and afternoon breaks will feature its own selection: the "Energy" Coffee Break (Saturday morning) will include Fraise Banane yogourt 'Smoothies', Tropical Mango-Orange 'Smoothies,' Clif Energy Bars, Individual bags of De Luxe Mix. The Homestyle Break (Saturday afternoon) will include freshly baked cookies. Danish pastries (Friday morning). The Health Coffee Break (Sunday morning) will include a fresh fruit salad, assorted yoghurts, and granola bars.

On Saturday, 13 October 2018, **lunch** is a buffet of sandwiches, including Montreal Smoked Meat (Hot sandwich), grilled chicken club, and grilled vegetables & pesto wrap. In addition, buffet will also have a fresh fruit salad, spring field mix and garnishes, roasted root vegetables, vegetable and kettle potato chips, and a chef's dessert creation. After the symposium on Sunday, 14 October 2018, no lunch is provided.

Networking Dinner

Saturday, 13 October 2018

Decca77

1077 Rue Drummond, Montréal
Québec H3B 4X4 Canada

All registered attendees are invited to attend the **networking dinner** at the Decca 77 (13-minute walk from Centre Mont-Royal; left). The dinner starts directly after the business session and is casual and included with registration (no guests, please).

The multicourse dinner starts with a series of canapés, including crunchy Vegetarian spring rolls, homemade focaccia with mozzarella Di buffala and pesto, beet salad with goat cheese, selection of smoked meats, and Korean salmon tartar in a sesame cone. Apart from the canapés, the dinner buffet will includes a station with marinated pulled duck, carved turkey, and roast beef as well as garlic mash, seasonal vegetables, and a mixed salad with balsamic dressing. Dessert offers two canapé: Chocolate mousse and Maple hot cake.

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Each guest will receive two drink tickets. 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. The Chef has also made arrangements for those with special dietary needs.

Abstracts

Deriving a Clinical Preference-Diagnostic Procedure from Large-Sample Choice-Experiment Data

F. Reed Johnson, PhD, Duke University; Juan Marcos Gonzalez, PhD, Duke University; Shelby Reed, PhD, Duke University

Purpose: The aim of this study was to derive a preference diagnostic procedure for shared decision making based on large-sample latent-class analysis of discrete-choice experiment data.

Methods: In a previous large sample study (N=814), Crohn's disease patients completed a series of choice questions that required evaluating pairs of constructed medical therapies. Scale-adjusted latent-class choice models identified three distinct preference classes: Efficacy Seeking (61%), Steroid Averse (25%), and Risk Averse (16%). Answers to 2 of 36 choice questions discriminated well among the three possible preference classes. A short-form version of the original instrument containing only 2 choice questions was deployed in a clinic setting to diagnose patient preference-class membership. Results were compared with convenience samples of health professionals.

Results: Combined answers to 2 questions predicted class membership with probabilities of 0.87, 0.97, and 0.87, respectively. When deployed in a clinical setting, answers to these questions assigned individual clinic patients in proportions similar to those in the original study. Post-exercise debriefing confirmed that patients were in agreement with the preference classifications made by the preference diagnostic procedure. In contrast to patients, the majority of health professionals completing the same two questions were assigned to the Risk-Averse class (0.68).

Conclusions: Large-sample choice-experiment studies increasingly are being used to inform decision making for product development and regulatory assessments. However, it is unclear what relevance such studies have for individual treatment decisions. This study demonstrates that investment in a large, good-practice choice experiment can be leveraged to construct a preference-diagnostic procedure that is simple and fast enough to inform shared decision making. Moreover, the assumption that health professionals' own assessment of benefit-risk tradeoff acceptability is a reasonable proxy may not hold for a majority of patient-caregiver dyads in Crohn's-disease healthcare. Finally, class assignment can be used as priors for adaptive-design identification of individual patient-preference parameters.

Adjusting for Scale Confounds in Preference-Sensitive Decisions: Does it Work?

Jay Magidson, PhD, Statistical Innovations Inc.

Introduction: Quantifying individual respondent preferences accurately is important for clinicians and public policy makers to develop useful decision aids to assist patients in preference-sensitive decisions. However, estimating preferences is problematic even in the preferred setting where best-worst scaling designs are used. Attributes with the highest Best-Worst score for many respondents may not be unique (due to ties). Latent class (LC) analysis avoids ties but may result in a class of less certain respondents, who differ in their preferences. Recently developed scale adjustment tools are increasingly being used, but have yet to be critically evaluated. In particular, Scale-Adjusted LC (SALC) purports to assign 'low scale' respondents to the most appropriate preference class, but has not been compared with Hierarchical Bayesian (HB) methods where scale is included as part of the estimated individual-level utilities.

Methods/Approach: We compare the use of Best-Worst scores with results obtained from standard LC, SALC and HB in a reanalysis of data from Louviere and Flynn (2010) to assess preferences for 15 healthcare reform principles. In particular, we evaluate whether the data support Flynn's hypothesis of 3 'policy-relevant' classes" – those who value 1) equity, 2) efficiency/value for money, and 3) investment in future health, and size these classes.

Results: The SALC model identified 31% of respondents to be of 'low-scale', exhibiting somewhat low response consistency. Adjusting for scale differences, SALC identified 3 preference classes that corresponded closely to those hypothesized by Flynn, and was able to size the classes. While HB yielded somewhat similar results, it assigned these 31% to substantially different preference classes.

Conclusions: Preference-sensitive decisions should rely on preference estimates free from scale confounds. SALC models offer a way to identify less consistent respondents and adjust for such scale differences to obtain better measurement, thus suggesting more appropriate decision aids for preference sensitive decisions.

Development and evaluation of an individualized decision aid for atrial fibrillation

Nick Bansback, PhD, School of Population and Public Health; James Hicklin, MSc, Pharmaceutical Sciences, University of British Columbia; Larry Lynd, PhD, Pharmaceutical Sciences, University of British Columbia; Shahrzad Salmasi, MSc, Pharmaceutical Sciences, University of British Columbia; Peter Loewen, PharmD, Pharmaceutical Sciences, University of British Columbia

Background: Stroke prevention therapy decisions in atrial fibrillation (AF) are complex and require trade-offs, but existing patient decision aids (PtDAs) have focused on individualized risks and not helping match preferences with options. The objective of this study was to evaluate whether a PtDA that integrates a Best Worst Scaling (BWS) exercise can improve patients' knowledge, clarify their values, and enable them to take a more active role in decision-making.

Methods: We developed an online individualized online AF stroke prevention therapy PtDA which integrated a BWS exercise based in individualized risks to both help individuals clarify values, and help direct which option is best for them. We tested the PtDA a prospective observational study involving AF patients and those at risk of AF. Validity and acceptability outcomes were decisional conflict (DCS), system usability (SUS), time to complete, correlations between stroke and bleeding risk and participant choices, and qualitative feedback. We also analyzed patients expressed values and preferences.

Results: 37 participants completed the study in a median of 27 minutes. The PtDA significantly increased participant AF knowledge ($p=0.02$) and decreased the DCS score all its subscales (all $p<0.01$). The mean SUS score was 61+15.2. Participants valued stroke prevention and major bleeding avoidance most highly, and diet/alcohol restrictions, number of daily doses, and cost least. Seventy-six percent of AF patients changed their preferred therapy, including 60% choosing therapy different from that currently prescribed. Qualitative feedback suggests the format of BWS results could be individualized in different ways to improve decision-making processes.

Conclusions: Our novel PDA was effective for increasing patients knowledge, reducing decisional conflict, clarifying patients' values, and presenting valid therapy options. Using the PDA caused many patients to change their preferred therapy and revealed therapy preferences different from that currently prescribed. The PDA is a practical and potentially valuable tool to facilitate shared decision about stroke prevention therapy for AF.

Dominance in Stated Choice Experiments: Scary Monster, Annoyance, or Nothing Burger?

Keith Chrzan, BA, Philosophy of Religion; MBA, Marketing, Sawtooth Software, Inc.

Background: Bliemer, Rose and Chorus (2014) illustrate how dominated choice sets can bias utilities to be larger. As a remedy, they propose a model with a scale factor that varies from choice set to choice set depending on whether the set contains a dominating alternative or not.

Methods: After creating a range of designs that vary in terms of the number of ordered attributes and the number of alternatives per set we find that dominance will have greater potential for trouble as the number of ordered attributes rises and the number of alternatives/set shrinks. The two empirical studies build on this finding. One study (n=206, 4x32x24 in 8 sets of triples) has seven attributes with preference-ordered levels and 5% of its choice sets are dominated. The second study (n=399, 42x3 in 10 sets of pairs) has 25% of its choice sets dominated.

Results: In Study 1 neither scale (chi squared=0.96 with 1 d.f., p=0.32) nor utilities (chi squared=18.93 with 12 d.f., p=0.09) differ significantly depending on dominance. Study 2 produces significant differences, but NOT those predicted by Bliemer, Rose and Chorus: its model coefficients differ significantly: (chi squared=25.84 with 9 d.f., p=0.0022), which prevents a test of differences in scale. Because scale differences are not what distinguish dominated and non-dominated choice sets in Study 2, the Bleimer, Rose and Chorus scale varying model will not be an appropriate remedy but a model indicating whether an alternative is dominated (1) or not (0) produces a model nearly indistinguishable from that includes only the non-dominated choice sets.

Conclusions: Dominance can affect the utilities from a stated choice experiment. Some design conventions can exacerbate the extent of dominance and its opportunity to influence preference parameters. A simple model including an indicator for dominated alternatives provides a post hoc remedy.

Risky Business: Benefit-Risk Tradeoff Measures for Concurrent Risks

Angelyn Otteson Fairchild, BA, Duke Clinical Research Institute; Juan Marcos Gonzalez Sepulveda, PhD, Duke Clinical Research Institute; F. Reed Johnson, PhD, Duke Clinical Research Institute

Introduction: Marginal Maximum Acceptable Risk (MMAR) estimates derived from discrete choice experiments have important regulatory applications—they provide rigorous quantitative evidence of the maximum probability of harm that patients are willing to bear to obtain treatment benefits. Conventional methods for calculating MMAR consider the probability of each harm in isolation with 0% probability assumed for other harms; thus MMARs for various risks are implicitly assumed to be additive. However, this assumption is not met when patients are exposed to multiple simultaneous adverse event risks.

Approach: We simulate MMAR estimates for two risks to identify the reduction in risk tolerance for one risk as the other risk increases. We explore several plausible relationships between risks to assess extent to which the resulting simultaneous MMAR estimates deviate from the conventional additively-separable MMAR estimate.

Results: For certain profiles, our models show that combined probabilities of harms would not be accepted by respondents, even though conventional single-risk MMARs could indicate that respondents would accept the profile. The magnitude of the difference between these approaches depends on the degree to which

marginal preferences differ across the range of probabilities, and the extent to which marginal preferences for one harm depend on the probability of another concurrent harm.

Implications: Calculating MMARs by assuming that risks can be evaluated individually is counter to clinical realities and results in over-estimating risk tolerance for treatments. If regulators make approval decisions based in part on these estimates, they may approve treatments that are in fact not acceptable to the relevant population. Some preference elicitation methods do not allow a joint estimation of MMARs and may require adjustments to more accurately characterize patients' tolerance for treatments. To deliver accurate MMAR estimates, researchers must account for increases in the probability of multiple harms that occur simultaneously in a single treatment decision.

From a different angle: a novel approach to modeling health preferences

Benjamin M. Craig, PhD, University of South Florida; **John D. Hartman**, PhD, University of West Florida; Mark Oppe, PhD, EuroQol Research Foundation

Background: To date, most DCE modelling are based on logits or probits. Alternatively, ratio- or angle-based models, such as Zermelo-Bradley-Terry (ZBT), may better estimate values using DCE responses. Aims: To compare the ZBT and logit models for the analysis of health preferences.

Methods: We examined DCE responses from seven EQ-VT studies: The Netherlands, China, Singapore, Spain, Canada, Uruguay and Korea. Each included the same 186 pairs generated with a Bayesian efficient design algorithm as well as 10 mild pairs that were manually selected. Each paired comparisons was designed such that both alternatives have a few attributes that make it better than its counterpart (i.e., opportunity cost: A, B > 0). The 196 pairs were divided over 28 blocks of 7 pairs, and randomized in sequence and on screen (left-right). Using data on the 186 efficient pairs, we estimated two models for each study. The logit assumes that the additive difference (A-B) is proportional to the log odds: P(A>B)=e^A/(e^A+e^B). The ZBT model assumes a power relationship between the ratio (A/B) and the odds: P(A>B)=A/(A+B). Each model included 20 main effects parameters for the levels and one ancillary parameter, was estimated by maximum likelihood with respondent-level clusters and evaluated by its predictive validity as well as the sign and significance of the level parameters. Furthermore, we examined their ability to discriminate between known groups, namely countries, and to predict the mean responses of the 10 mild pairs.

Results: Overall, the ZBT produced fewer disordered levels (0 vs. 8) and fewer insignificant parameters (p-value<0.01; 5 vs. 32) compared to the logit. Across the seven countries, ZBT produced a higher pseudo-likelihood and found more differences between level parameters by country (p-value<0.01; 109 vs. 86). For the 10 mild pairs, the logit poorly predicted the mean responses (Pearson's rho 0.350; Lin's concordance 0.102), but ZBT predicted these mean responses well (Pearson's rho 0.744; Lin's concordance 0.698).

Conclusions: Based on the evidence from seven countries, ratio- or angle-based models (e.g., ZBT) appear to fit EQ-VT paired comparison responses better and produce fewer inconsistencies between levels. With improved fit and content validity, differences between countries became more evident.

How common and how useful are debriefing questions in health economics DCEs?

Alison Pearce, , CHERE, University of Technology Sydney; Brendan Mulhern, , CHERE, University of Technology Sydney; Verity Watson, , HERU, University of Aberdeen; Rosalie Viney, , CHERE, University of Technology Sydney

Background: Debriefing questions are used to test whether DCE respondents comprehend the choice task and act in the way rational decision making assumes (e.g. continuity, completeness). However, little is known about how effective debriefing questions are in identifying 'irrational' responders or evaluating comprehension. We aimed to identify the frequency and type of debriefing questions used and assess if common debriefing questions identify people likely to respond 'irrationally'.

Methods: We surveyed 168 authors of published health DCEs about the debriefing questions they included, and how the responses were used. We then collated data from 6 completed DCEs with similar debriefing questions. Multiple regression was used to identify characteristics associated with answers indicating potentially 'irrational' responses. A health state valuation data set was further analysed to assess whether the underlying preference scale varied by debriefing responses.

Results: 70 authors completed the survey and 66% reported using debriefing questions. Most addressed difficulty (91%) or understanding (49%) of the DCE, with considerable variation in the wording used. Only 37% of authors reported analysing the responses, usually to exclude respondents or aid overall DCE interpretation. The six DCEs with common debriefing questions had 5,460 respondents in total. Between 13% ("difficulty with task") and 45% ("did not consider all attributes") of debriefing responses indicated potential 'irrationality'. Older and less educated respondents were more likely to report using a strategy to make choices, and less likely to report attribute non-attendance. There was no evidence that debriefing responses were associated with underlying scale heterogeneity.

Conclusions: While many DCEs include debriefing questions, the responses are often not used. While it appears some debriefing questions capture aspects of rational decision making, many do not seem particularly sensitive to irrational choice behaviour. Further work is required to identify a set of debriefing questions that would be useful in health-related DCEs.

Internal-validity checks in a stated-preference study: implications on preferences & valid responses

Rachael L. DiSantostefano, MS, PhD, Janssen R&D, LLC; Shelby D. Reed, PhD, Department of Population Health Sciences, Duke University, Durham, NC, USA; Jui-Chen Yang, MEM, Duke Clinical Research Institute, Duke University, Durham, NC, USA; Bennett Levitan, MD, PhD, Janssen R&D, LLC; F. Reed Johnson, PhD, Department of Population Health Sciences, Duke University, Durham, NC, USA

BACKGROUND: Best practices in patient preference studies include internal-validity checks for "logical soundness" of stated-preference data. However, there is no standard approach to handling validity-test failures when analyzing data from choice experiments. OBJECTIVES: To evaluate the impact on preferences pertaining to benefits and risks of treatments that could delay onset of Alzheimer's disease (AD) symptoms when applying different approaches to addressing internal validity-test failures.

METHODS: 1004 participants completed a web-enabled stated-preference survey in which they were to suppose that they would develop AD in the future. Options included a fixed no-medication alternative or a hypothetical treatment alternative with varying benefits, side effects, and risks. A dominated-pair question offered a treatment alternative that provided no additional treatment benefit but had significant risks

relative to no medication. Choices were analyzed using a random parameters logit model. A binomial probit model was used to identify predictors of always choosing AD treatment.

RESULTS: On average, respondents were more concerned with preserving normal memory than risks of AD treatment. The maximum acceptable risk (MAR) of death for one more year of normal memory was 13% overall. When excluding participants failing the dominated-pair question (30%), MAR of death was 7%. When excluding participants who always chose treatment or failed the dominated-pair question (38%), MAR of death was 3%. The number of times that the treatment alternative was selected across the 8 choice tasks was positively correlated with failing the dominated-pair test (rho=0.89). Participants always choosing AD treatment were more likely to have provided recent AD care (p=0.006).

CONCLUSIONS: Participants in our study may have understood the choice tasks and been revealing a preference for any treatment that could delay AD symptoms rather than simply failing an internal-validity question. Interpreting the impact of addressing validity-test failures in practice requires an understanding of the choice context.

Comparison of three contingent valuation techniques: The case of ovulation induction in Quebec

Thomas G Poder, PhD, CIUSSS de l'Estrie - CHUS; Aissata Dieng, MSc, Université de Sherbrooke; Jie He, PhD, Université de Sherbrooke

Introduction: Anovulation or failed ovulation is one of the main causes of infertility in women. The aim of this study is to compare the willingness to pay (WTP) of women of childbearing age to receive drug treatment in the event of failed ovulation according to 3 different contingent valuation methods (CVM).

Methods: Three elicitation techniques were used: simple bid price dichotomous choice (DC), DC followed by an open-ended question (DC-OE) and bidding game (BG). Each participant was randomly allocated to one of the 3 elicitation techniques. Bid prices ranged from $200 to $5,000 Canadian dollars. Of the seven bid prices, one was randomly proposed to each participant in DC and DC-OE groups. For DC-OE, if the first answer was "no", respondents were asked their maximum WTP. For BG, each respondent was offered an initial bid price of $1500 and subsequent bid price offered increased or decreased according to the answer provided. The "do not know" responses were considered as "no" and a question about the certainty of the answer was asked after each choice. WTP values were estimated using probit and bivariate models. The Welsh and Poe model was also used for BG.

Results: An online survey was conducted with 680 women. Analyses were performed on 610 respondents (199 DC, 230 DC-OE, 181 BG). The mean WTP values were $4,033.26, $1,857.90 and $1,630.63 for DC, DC-OE and BG, respectively. The WTP for BG "Definitely Yes" and "Probably Yes" were $1516.73 and $1871.22. The three elicitation techniques provided statistically significant different WTP values (p<0.01). BG was the more accurate method with lower confidence interval ($557) and lower (CI/mean) ratio (0.34).

Conclusion: Adding a follow-up question resulted in more accurate WTP values. BG technique provided a more accurate estimate of the WTP with a smaller confidence interval.

Women's Health: Do patients with advanced breast cancer care about TTP independent of OS?

Axel C. Mühlbacher, PhD, Health Economics and Health Care Management, Hochschule Neubrandenburg, Germany; Christin Juhnke, MA, Health Economics and Health Care Management, Hochschule Neubrandenburg, Germany; Andrew Sadler, MSc, Health Economics and Health Care Management, Hochschule Neubrandenburg, Germany

Background: Endpoints based on the assessment of the tumour include progression-free survival (PFS), Time to Progression (TTP) and overall survival (OS). While OS measures survival time in general, PFS includes tumour progression assessment in addition to survival time. Discussions arose on whether to use both endpoints in clinical trials and whether patients differentiate between them.

Methods: The study aimed to quantify patients preferences for both endpoints of treatments in women with advanced or metastatic breast cancer in Germany. Within a discrete choice experiment the interaction between OS and TTP was modelled as a two-dimensional compound attribute defined by six levels to represent the impact on preferences of a change in TTP at different levels of OS.

Results: 'TTP/OS' was the most important favourable effect with the highest relative importance for N=233 patients with advanced or metastatic breast cancer. The compound attribute was consistent with the expected ordering of the categories; e.g.50-month OS is rated higher at 5 months without progression than 30 months OS/25 months without progression. "25 months without progression/30 months OS" is rated equally to "5 month without progression/40 month OS". Respondents always preferred higher TTP to a lower TTP independent of the level of 'OS'. When keeping OS constant, TTP was shown to independently impact treatment choices by respondents.

Conclusions: Suitability of PFS as surrogate endpoint is controversial. This study revealed that compound attributes may represent a possible approach to document the value of TTP. The value to patients can be demonstrated independently of the causal relationship between these two trial endpoints. Changes in the level of TTP positively impacted respondents' choices independent of OS. Hence, TTP can be seen as an independent decisive factor.

What Australian gay and bisexual men want from HIV self-test kits: a discrete choice experiment

Jason Ong, PhD, MMed, MBBS, FRACGP, FAChSHM, London School of Hygiene and Tropical Medicine, Monash University (Australia); Richard De Abreu Lourenco, PhD, CHERE, University of Technology Sydney; Deborah Street, PhD, CHERE, University of Technology Sydney; Muhammad Jamil, PhD, The Kirby Institute, University of New South Wales; Kirsty Smith, PhD, The Kirby Institute, University of New South Wales; Fern Terris-Prestholt, PhD, London School of Hygiene and Tropical Medicine; Rebecca Guy, PhD, The Kirby Institute, University of New South Wales

Background: HIV self-testing (HIVST) can increase HIV testing among gay and bisexual men (GBM). We assessed the preferences of Australian GBM for HIVST relative to other testing methods, and for how to access HIVST.

Methods: We conducted a discrete choice experiment (DCE) among HIV-negative GBM age ≥18 years in January 2018 through Grindr advertisements. Men were randomized to one of two DCEs which included a series of 16 choices, each with two alternatives for HIV testing: DCE1 for HIVST kit attributes (price, accuracy, test type, collection method and who collects the specimen) and DCE2 for HIVST access attributes (price, location, packaging and usage instructions). Latent class conditional logit regression explored variability in

preferences among infrequent testers (tested >2 years ago or never tested), recent migrants (arriving in Australia <5 years), students, country of birth and number of partners in the last 6 months.

Results: Overall, 727 men participated in DCE1 and 275 men participated in DCE2. DCE1 contained four classes of men: 'one sexual partner' (prefer high accuracy tests, class size 17%); 'infrequent testers and students' (prefer fast results and oral HIVST, class size 28%); 'recent migrants' (prefer fast results and cheaper tests, class size 23%); and 'frequent testing Australian-born men with multiple partners' (prefer tests with shorter window periods and finger-prick HIVST, class size 33%). DCE2 contained three classes of men: 'price matters' (prefer purchasing kits online or off-the-shelf from pharmacies, class size 48%), 'infrequent testers' (prefer purchasing kits online and vending machines, class size 35%) and 'frequent testers' (disliked purchasing online and prefer purchasing off-the shelf from pharmacies or staff from medical clinics, class size 17%).

Conclusion: Maximizing uptake of HIV testing among Australian GBM requires tailoring of reach strategies to account for heterogeneous preferences related to HIV testing services and how they would like to access HIVST.

Patients' and Caretakers' Treatment Preferences in the End-of-Life Setting

Aaron B Cohen, MD, University of Pennsylvania; Juan Marcos Gonzalez, PhD, Duke University; Ronac Mamtani, MD, MSCE, University of Pennsylvania; Meenakshi Bewtra, MD, MPH, University of Pennsylvania

Background: Although patients with incurable cancer are expected to evaluate treatment alternatives with their oncologists, real-world decision making at the end of life likely includes the perspectives of other stakeholders such as caretakers. There is little evidence on patients' relative preferences for outcomes of active treatment and supportive care, and even less information on how patients' views correlate with those of their caretakers.

Methods: A web-enabled DCE was administered to patients with incurable solid malignancies and their caretakers. We used a three-alternative labeled design (two chemotherapies and supportive care) with varying prognosis for expected survival, chance of serious infections, severity of pain, and expected functional limitations. Group-specific preference weights were estimated and used to calculate the minimum number of additional months of survival respondents would require to make a specific intervention acceptable (MAB). Additionally, we assessed the correlation of choices for each dyad to evaluate decision-making agreement at the individual level.

Results: A total of 71 patients and 30 caretakers completed the DCE instrument. Aggregate-level preference weights show that severe pain and functional limitations were statistically more important to patients than extending survival by 18 months (P<0.01). On average, functional limitations (MAB 28.7 months, 95% CI: 17.7—39.5 months) were perceived to be more important than pain (MAB 26.1 months, 95% CI: 16.9—35.4 months) by caretakers. This was not the case for patients. The risk of infection was the least important attribute for both patients and caretakers. Correlation among patients' and caretakers' choices was 0.65.

Conclusion: Patients and caretakers generally agreed on their stated preferences for treatment outcomes and their treatment choices. Preference weights suggest that health status during life extensions affects respondents' willingness to consider active treatment. Among patients, the ability to perform daily activities was a primary concern, whereas pain was more concerning to caretakers.

[α] indicates an IAHPR member

Abstract Guidelines and Instructions

6 August 2018
Derek S. Brown, Benjamin M. Craig
RE: Abstract Guidelines and Instructions

As the IAHPR Scientific Committee, we encourage the submission of abstracts that introduce new ideas, concepts, methods and evidence to health preferences research, as well as policy- or clinically-relevant findings. Abstracts related to symposium topics are particularly welcome.

For an empirical quantitative study, its abstract must demonstrate that the data, study design and analyses were appropriate for the aims and that the conclusions are consistent with the results. Such an abstract must include actual findings, not just proposed or intended analyses. Methodologic creativity and innovations are encouraged.

Beyond such studies, the Committee also welcomes other forms of health preference research, such as: (1) novel conceptual abstracts with strong implications; (2) the development and application of support tools for preference-sensitive decisions, such as decision aids; and (3) methodologic comparisons, such as simulation and secondary analyses. Abstracts on pioneering extensions of the stated- and revealed-preference conceptual frameworks are encouraged (with or without empirical results).

Please read the following guidelines carefully before submitting your abstract:

- Abstracts can only be submitted online via our website (http://iahpr.org); submissions by fax, post or email will not be considered. Abstracts will not be eliminated administratively unless entirely unsuitable (e.g., duplicates, withdrawals). However, the submission of multiple abstracts on the same study is discouraged.
- The presenter must attest that the work is original and that all co-authors have reviewed the submitted abstract and agree to its final form. The presenter must also indicate:
    - Abstract type: Preferences between Health Outcomes; Preferences between Health-related Goods and Services; Preference Elicitation Tasks and Analysis; Preference Tools and Technologies; or Other;
    - Whether the presenter is a student or post-doctoral fellow;
    - Whether the abstract pertains to the symposium topic; and
    - Whether the presenter is willing to share their slides.

  It is the responsibility of the reviewers to take these attributes into account in their ratings.
- It is the presenter's responsibility to submit a correct abstract. Any errors in spelling, grammar or scientific fact in the abstract text will be reproduced as typed by the presenter. Abstract titles may be subject to a spell check if the abstract is selected for presentation.
- All tenured IAHPR members will have the opportunity to review and comment on all abstracts. The Foundation Chair and the Scientific Director will tally the reviewer ratings and comments (similar to elections) and compute the mean score of each abstract: 5×Superior + 3×Good + 2×Acceptable - 5×Unacceptable. Unless a presenter has multiple highly ranked abstracts, the twelve abstracts with the highest mean score will be invited for podium presentation. If there are three or more additional abstracts with mean score greater than 2.0 (Acceptable), these acceptable abstracts will be invited for poster presentation.

Tenured Members in Attendance

Kathy Beusterien, MPH, *Senior Research Scientist, Kantar Health, Washington DC, USA*

Download CV

Summary

Kathleen M. Beusterien, MPH, founder of Outcomes Research Strategies in Health (ORS Health), has over 20 years of experience performing health outcomes research. Key areas of expertise include developing and implementing clinical outcomes assessment (COA) measurement strategies, patient and physician preference/conjoint studies, and health status utility studies. Kathy has consulted on a number of communications with the FDA and EMA regarding patient reported outcomes (PRO) endpoints in clinical trials and has developed PRO measures and dossiers for regulatory review. Kathy has held senior leadership positions at outcomes research consulting firms, including UBC and Oxford Outcomes, where she opened and grew the US PRO consulting practice. She has numerous PRO and preference publications and regularly leads workshops and presentations at scientific and industry conferences on these areas. Kathy received a Masters in Public Health in epidemiology and a Bachelor of Science in physiological psychology from the University of Michigan.

Country

United States

IAHPR Membership

Founding IAHPR Member

Meenakshi Bewtra, MD, MPH, PhD, *Assistant Professor of Medicine and Epidemiology, University of Pennsylvania, Philadelphia, USA*

Summary

Meenakshi Bewtra, MD MPH PhD is an Assistant Professor of Medicine and Epidemiology and Senior Scholar in the Center for Clinical Epidemiology and Biostatistics at the University of Pennsylvania Perelman School of Medicine. Dr. Bewtra has been conducting clinical research for over 10 years in inflammatory bowel disease (IBD) with a focus on natural history; outcomes of disease and medication safety using observational data and statistical modeling; measures of risk and risk tolerance using discrete choice experiment; and clinical trials for novel interventions. Dr. Bewtra is the PI of the IBD-Immunology Initiative (I3), a prospective clinical and tissue IBD biobank examining the basic mechanisms of IBD and predictors of response to therapies with the goal of improving personalized medicine in IBD. Dr. Bewtra's work has been funded by the NIH, CCFA, AGA, PCORI, pharmaceutical industries, and private philanthropy. She is currently a member of the CCFA, the AGA and the ACG.

Country

United States

IAHPR Membership

Founding IAHPR Member

John Bridges, PhD, *Professor, The Ohio State University, Columbus, USA*

Download CV

Summary

Dr. Bridges is an Associate Professor in the Department of Health Policy and Management and International Health at the Johns Hopkins Bloomberg School of Public Health where he also serves as the co-Director of the Masters of Health Science in Health Economics and is a core-faculty member of the Center for Health Services and Outcomes Research.

Country

United States

IAHPR Membership

Founding IAHPR Member

Derek S Brown, PhD, *Associate Professor, Washington University in St. Louis, St Louis, USA*

Download CV

Summary

My research focus on public health and social policy applications of discrete choice experiments (DCEs) and health-related quality of life (HRQOL). I am interested in health valuation, health preferences, and economic evaluation. Specific topics that I have worked in for health preferences include: vaccines (HPV and general pediatric), child maltreatment, long-term care insurance, HIV screening, colorectal cancer screening, genetic screening newborn screening, valuation of multiple HRQOL instruments, and food safety. I have conducted DCEs in the US, China, and Tanzania.

Country

United States

IAHPR Membership

Founding IAHPR Member

Keith Chrzan, BA, Philosophy of Religion; MBA, Marketing, *SVP Analytics, Sawtooth Software, Inc., Provo, USA*

Visit Scientist's website

Summary

Keith is Senior Vice President of Analytics at Sawtooth Software, Inc. For the decade before joining Sawtooth Software he was SVP/Chief Research Officer at Maritz Research. Keith has a BA in Philosophy of Religion from Notre Dame in 1981 made marketable by an MBA in Marketing from Indiana University in 1983. Experienced in all manner of analytics related to survey marketing research, his particular interests are in the areas of choice modeling and choice experiments. Keith is a Member of the American Marketing Association and INFORMS, the Institute for Operations Research and the Management Sciences.

Country

United States

IAHPR Membership

Tenured IAHPR Member Since 2016

Benjamin M Craig, PhD, *Associate Professor, University of South Florida, Tampa, USA*

Download CV

Visit Scientist's website

Summary

Benjamin M. Craig, PhD, is an Associate Professor of Economics at the University of South Florida. He received his MS in Economics at the University of Texas at Austin in 1999 and his PhD in Population Health from the University of Wisconsin in 2003. His research focuses on health preference research and cancer economics with an emphasis on experimental design and analysis. He regularly teaches health economics, econometrics and outcomes research. In addition to IAHPR and the EuroQol Group, Benjamin is an active member of the International Health Economics Association (iHEA), the American Society of Health Economists (ASHE), the International Society for Pharmacoeconomics and Outcomes Research (ISPOR), and the International Society for Quality of Life Research (ISOQOL).

Country

United States

IAHPR Membership

Founding IAHPR Member

Juan Marcos Gonzalez, PhD, *Assistant Professor, Duke University, Durham, USA*

Download CV

Summary

Juan Marcos González Sepúlveda, Ph.D., has experience in research in health and environmental economics. His areas of expertise are econometrics and discrete-choice analysis of revealed- and stated-preference data.

Country

United States

IAHPR Membership

Founding IAHPR Member

Ellen Margreet Janssen, PhD, *Principal, Patient Centered Outcomes, ICON plc, Gaithersburg, USA*

Download CV

Summary

Ellen M. Janssen is a health economist focused on valuing healthcare interventions and outcomes. She has worked with quantitative and qualitative methods to value the cost of behavioral interventions and to measure the preferences and priorities of patients across a wide spectrum of healthcare questions including treatment preferences, communication strategies, and risk prioritization. Ellen is passionate about engaging patients as research partners in all levels of healthcare decision-making. As such she has worked with a variety of patient and community groups, as well as regulatory experts at FDA in her research. Her current work examines good research practices for the development, implementation, analysis, and evaluation of stated-preference methods to ensure that patient preference studies are transparent and meet high quality standards.

Country

United States

IAHPR Membership

Tenured IAHPR Member Since 2018

F. Reed Johnson, PhD, *Professor, Department of Population Health Sciences, Duke University, Duke Clinical Research Institute, Durham, USA*

Download CV

Summary

Dr. Johnson has over 40 years of academic and research experience in health and environmental economics and currently am the most senior expert in the field of health applications of stated-preference research. He has served on the faculties of several universities in the United States, Canada, and Sweden, as Distinguished Fellow at Research Triangle Institute, and currently as Professor in Medicine at the Duke Clinical Research Institute, Duke University. As a staff member in the US Environmental Protection Agency's environmental economics research program during the 1980s, he helped pioneer development of basic nonmarket valuation techniques. These techniques now are widely used for benefit-cost and benefit-risk analysis in health and environmental economics.

Dr. Johnson also has pioneered applications of advanced stated-preference methods to quantify patients' and caregivers' preferences for health-care outcomes. His current research involves estimating general time equivalences among health states and patients' willingness to accept side-effect risks in return for therapeutic benefits. He led the first FDA-sponsored study to quantify patients' willingness to accept benefit-risk tradeoffs for new health technologies. The results are being used to inform reviews of regulatory submissions and helped support recent FDA guidance on incorporating patient preferences in regulatory assessments of new health technologies.

At Duke Dr. Johnson has worked closely with Dr. Shelby Reed to establish a new Preference Evaluation Research Group (PrefER) in the Duke Clinical Research Institute's Center for Clinical and Genetic Economics. His appointment in Duke Medicine has facilitated access to and collaborations with leading clinical experts in orthopedics, neurology, psychiatry, oncology, dermatology, and cardiology, as well as access to patient respondents receiving care in the Duke healthcare system.

Country

United States

IAHPR Membership

Founding IAHPR Member

Chrissy Kistler, MD, MASc, *Associate Professor, UNC Family Medicine, Chapel Hill, USA*

Download CV

Summary

I am a board-certified Family Medicine physician, with added certifications in Geriatrics and Hospice and Palliative Medicine. I have a Master's degree from UCSF in clinical research and am a health services investigator with a focus on improving the appropriateness of medical decision-making. I have additional expertise assessing the quality of care older adults receive though my training with the Veterans' Affairs Quality Scholars program. My work has examined decision-making and explicitly examines the appropriateness of treatment decisions in these contexts, especially for older adults. I have conducted research examining clinical decision-making in cancer control and prevention, and infection control.

Country

United States

IAHPR Membership

Founding IAHPR Member

Deborah A Marshall, PhD, *Professor, University of Calgary, University of Calgary, Calgary, Canada*

Summary

Deborah Marshall holds a Canada Research Chair, Health Services and Systems Research as an Associate Professor at the University of Calgary and Arthur J.E. Child Chair of Rheumatology outcomes Research in the McCaig Institute of Bone
and Joint Health and the Institute of Public Health. She has experience in technology assessment agencies, academia and pharmaceutical and diagnostics industry research settings in Canada, the United States, and Europe. Her research program focuses on health technology assessment – specifically patient preferences, cost-effectiveness analysis, and health systems modeling. Dr. Marshall is an active member of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) as the Past President of the Board of Directors and as a member of the Patient Preferences Special Interest Group and coauthor of ISPOR Task Force Reports on Good Research Practice focusing on Conjoint Analysis Applications in Health, Experimental Design and Analysis.

Country

Canada

IAHPR Membership

Founding IAHPR Member

Axel Christian Mühlbacher, PhD, *Professor, Hochschule Neubrandenburg, Neubrandenburg, Germany*

Download CV

Summary

Axel Mühlbacher, Dr. rer. oec., Dipl. Kfm., is a professor of health economics and health care management at Hochschule Neubrandenburg. Since 2012, he has been a Senior Research Fellow at the Center for Health Policy & Inequalities Research at Duke Global Health Institute at Duke University, Durham, North Carolina, USA. Axel Mühlbacher was a 2010--11 Harkness Fellow in Health Care Policy and Practice at Duke Clinical Research Institute and Fuqua School of Business, Duke University.

Prior to founding the Institute of Health Economics and Health Care Management at Hochschule Neubrandenburg in 2006,
Axel had been an assistant professor in the department of economics and management at Technical University Berlin (2001¬-2004) and an associate professor of economics, health economics, and econometrics (C2) at Hochschule Neubrandenburg (2004-¬2006).

Axel's research focuses on patient preferences, comparative effectiveness/economic evaluation methods, and organized health care systems. Between 2009 and 2013, he was head of the pilot study on "conjoint analysis" on behalf of the German Institute for Quality and Efficiency in Health Care (IQWiG).

In 1996 he graduated from the Eberhard-Karls University, Tübingen, where he earned a degree in business administration and economics. That same year, he was appointed as a research fellow at the German Coordinating Agency of Public Health (GCAPH) at Albert-Ludwig University, Freiburg. In 1999 he joined the research training group, "Demand-¬oriented and cost-¬effective Health Care Fundamentals of optimal Allocation" (Graduiertenkolleg), at FU, HU, TU Berlin, with a scholarship from the German Research Foundation (DFG). In 2001 he graduated with a doctorate in economics and business administration (Dr. rer. oec.), with a thesis on "Management and organization of integrated care ¬an economic analysis of health care delivery networks" (summa cum laude).

Country

Germany

IAHPR Membership

Founding IAHPR Member

Jan Ostermann, PhD, *Associate Professor, Arnold School of Public Health, Columbia, USA*

Download CV

Summary

Dr. Ostermann is an associate professor at the Arnold School of Public Health at the University of South Carolina, and adjunct associate professor at the Duke Global Health Institute and Duke University's Center for Health Policy and Inequalities Research. I hold a PhD in Health Policy and Administration with a minor in economics. I have engaged in domestic and international research and evaluation for more than a decade. My research focuses on the intersection of health policy and health economics, involves children and adults, and includes observational and intervention studies in high, low, and middle income countries.

Country

United States

IAHPR Membership

Founding IAHPR Member

Shelby D. Reed, PhD, RPh, *Professor, Duke Clinical Research Institute, Durham, USA*

Download CV

Summary

Shelby Reed, PhD, RPh has nearly 20 years of experience leading multidisciplinary health outcomes research with a focus on economic and health policy evaluations. Dr. Reed has extensive expertise in designing and conducting trial-based and model-based cost-effectiveness analyses of medical diagnostics and therapeutic interventions. Her research has increasingly focused on stated-preference studies to evaluate benefit-risk tradeoffs, patient-centered value, and their application in clinical decision making. She is a Professor in the School of Medicine at Duke University and Director of the newly-formed Preference Evaluation Research (PrefER) Group at the Duke Clinical Research Institute. She is currently serving as President-Elect of ISPOR.

Country

United States

IAHPR Membership

Founding IAHPR Member

Mo Zhou, PhD, *Associate, Analysis Group, Boston, USA*

Summary

Mo Zhou, PhD is Associate at Analysis Group in Boston, Massachusetts. Her research interests include choice modeling, preference heterogeneity, econometrics, physician practice patterns, and economic evaluation of medical technologies.

Country

United States

IAHPR Membership

Tenured IAHPR Member Since 2018

Leslie Wilson, PhD, *Professor University of California San Francisco, University of California San Francisco, San Francisco, USA*

Summary

Dr. Leslie Wilson is an Adjunct Professor in the Departments of Medicine and the Department of Clinical Pharmacy, School of Pharmacy at the University of California, San Francisco. Dr. Wilson received her PhD in health policy and economics from the University of Maryland. Her current research focuses on preference analysis of patient decision making involving weighing risks and benefits in patients with multiple sclerosis. She also conducts economic and outcome analyses including cost of illness and cost effectiveness analyses of Cancer, HIV and specific chronic diseases (including rare diseases) and how new diagnostics, treatments and patterns of care affect the costs and outcomes of these diseases. She looks at the epidemiology, risks and economics of Chagas disease and its treatment in developing countries and in the U.S. blood supply, the economics of Valley Fever and the economics of genomics in screening and treatment and the effects of patient decision making on treatment choices. In addition, Dr. Wilson studies the economics of policy issues, including how drug legislation affects within California Workers' Compensation, and payment models for new models of dementia care. Dr. Wilson is the Codirector of the Health Services and Policy Research Pathway in the School of Pharmacy. She looks at the economic effects of new digital health aids on HIV and cancer patients. She teaches a course on decision analysis modeling and an elective and independent study on research in health economics. She is the developer and CoDirector of the Program for Pharmaceutical Economics and Policy Studies (ProPEPS) whose purpose is to organize the development of economic and policy research, teaching, and funding within the Department of Clinical Pharmacy.

Country

United States

IAHPR Membership

Founding IAHPR Member

Regular Members in Attendance

John Hartman, PhD, Clinical Assistant Professor, University of West Florida, Pensacola, USA

Bennett Levitan, MD-PhD, Senior Director, Epidemiology/Benefit-Risk, Janssen R&D, Titusville, USA

Alison Pearce, PhD, Chancellor's Postdoctoral Research Fellow, Centre for Health Economics Research and Evaluation, University of Technology Sydney, Sydney, Australia

Thomas G. Poder, PhD, Researcher, Centre de recherche du CHUS, CIUSSS de l'Estrie - CHUS, Sherbrooke, Canada

Janine Astrid van Til, PhD, Assistant Professor, University of Twente, Enschede, the Netherlands

Other Attendees

Sophy Barber, BDS, MSc, NIHR Doctoral Research Fellow, Leeds Teaching Hositals NHS Trust and University of Leeds, Leeds, England

Suzana Karim, PhD Student, Graduate Assistant, UNIVERSITY OF SOUTH FLORIDA, Tampa, USA

Jiat Ling Poon, PhD, Senior Research Scientist, Eli Lilly and Company, Indianapolis, USA

Stephanie Michelle Thomas, PhD Economics, Lecturer, Curtin University, Perth, Australia

Oliver Will, PhD, Research Scientist, Kantar Health, Horsham, USA

Min Yang, MD, PhD, Manager, Analysis Group, Inc., Boston, USA
Nick Bansback, PhD, Associate Professor, University of British Columbia, Vancouver, Canada
Aaron Benjamin Cohen, MD, MSCE, Research Oncologist, Flatiron Health, Flatiron Health, New York, USA
Rachael L. DiSantostefano, MS, PhD, Senior Director, Benefit-Risk / Epidemiology, Janssen R&D, LLC, Chapel Hill, USA
Angelyn Otteson Fairchild, BA, Research Consultant, Duke Clinical Research Institute, Durham, USA
France Légaré, MD, PhD, CMFC, Canada research Chair, Full Professor, Université Laval, Québec, Canada
Jay Magidson, Ph.D., President, Statistical Innovations Inc., Belmont, USA
Jason Ong, PhD, MMed, MBBS, FAChSHM, FRACGP, Associate Professor (Hon), London School of Hygiene and Tropical Medicine, London, United Kingdom
Jeff Alan Sloan, Ph.D., Professor of Biostatistics and Oncology, Mayo Clinic, Rochester, USA

Future Meetings

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**
Volkhaus, Basel, Switzerland
Workshop: "*Good research practices for health preference studies*" Axel C. Mühlbacher
Symposium: "*Patient preferences in medical treatment lifecycle*" Nigel Cook, Michael Drummond, Mandy Ryan

11th Meeting of the International Academy of Health Preference Research
2-3 December 2019, chaired by **Richard De Abreu Lourenço** and **Elisabeth Huynh**
Cliftons, Auckland, New Zealand
Workshop: "*Good research practices for health preference studies*" Kirsten Howard, Emily Lancsar
Symposium: To be determined…

12th Meeting of the International Academy of Health Preference Research
16-18 October 2020, chaired by **Ateesha Farah Mohamed** and **Shelby D. Reed**
To be determined, Chicago, Illinois, USA

13th Meeting of the International Academy of Health Preference Research
2021, chaired by **Michał Jakubczyk** and **Jorien Veldwijk**
To be determined, Europe

15 November 2017

Benjamin M. Craig, Chair

Emily Lancsar, Director of Outreach

2018 Outreach Program

During the Business Session at the 7th IAHPR Meeting in Glasgow, members noted that that it would be beneficial that the Academy (1) coordinate the submission of organized sessions to the meetings of collaborating organizations; (2) establish health preference research special interest groups within collaborating organizations; (3) better communicate forthcoming events at meetings of collaborating organizations; and (4) expand the dissemination of announcements beyond the current members.

At this time, collaborating organizations include:

1. International Society For Pharmacoeconomics and Outcome Research (ISPOR; Amsterdam 2014, Singapore 2016, Glasgow 2017)
2. Australian Health Economics Society (AHES; Brisbane 2015; Hobart 2018)
3. Society for Medical Decision Making (SMDM; St. Louis 2015; Montreal 2018)
4. European Association of Health Economics (EuHEA; Hamburg 2016)
5. International Health Economics Association (iHEA; Boston 2017; Basel 2019)

In addition to these, the Academy has collaborated with:

1. EuroQol Group (i.e., DCE Predictive Modeling Competition)
2. Sawtooth Software (i.e., sponsor of first meeting in Amsterdam)
3. ISOQOL (i.e., assistance on HPSTR from Health Preference Research SIG)
4. PREFER (i.e., joint symposium and workshop in Basel 2019)

The aim of our Academy is "to improve decisions about health and healthcare throughout the world by developing, promoting, and supporting health preference research with the widest possible applicability." A key component of our mission is "To foster and support an international community of researchers whose activities support health preference research." In concordance with these directives, we propose two initiatives as part of the 2018 Outreach Program:

1. Encourage IAHPR members to create, join, participate in and lead HPR SIGs at ISPOR, iHEA and SMDM (see Appendix). ISOQOL and EuroQol have HPR SIGs and have IAHPR leadership. EuHEA and AHES do not have any SIGs yet. To aid member endeavors, the Academy can offer to coordinate joint programs (e.g., webinars), arrange member surveys, and communicate SIG activities among IAHPR members. Furthermore, it is important to celebrate the accomplishment of HPR SIGs within the IAHPR community (e.g., news posts on the IAHPR website).

2. Coordinate the submission of organized sessions to AHES, IHEA and SMDM. These correspond to the next three IAHPR meetings. The purpose is to promote HPR at each organization's meeting and facilitate the presentation of preference research methods more broadly.

Appendix

iHEA - Call for Proposals to Establish a Special Interest Group
https://www.healtheconomics.org/news/363415/Call-for-Proposals-to-Establish-a-Special-Interest-Group.htm

iHEA is calling for proposals to establish Special Interest Groups (SIGs) that would provide a platform for professional interaction between iHEA members.These may focus on specific health economics research issues, methodological approaches and/or capacity development initiatives. They may also have a geographic focus, e.g. the economics of NCDs in Africa, including researchers working on this issue but based in a wide range of countries; or researchers based in a particular country or region. We particularly encourage proposal(s) to establish a student and/or early career researcher special interest group(s). Organizing and participating in collegial activity related to a topic of common interest offers tremendous professional growth opportunities and intellectual rewards.

SIGs approved by the iHEA Board will be offered:

- A page on the iHEA website to advertise SIG activities to all;
- A moderated blog or discussion list for iHEA members who join the SIG (summarized updates would be available to anyone interested);
- Support in communicating via the iHEA mailing lists and social media channels;
- Support for webinars for iHEA members; and
- A special organized session at the biennial iHEA congress, after review via the Scientific Committee process.

Proposals should include the following information:

- Proposed name of the SIG;
- Background: Explain the focus of the proposed SIG, why the area of focus is of particular importance and why it is likely to be of interest to iHEA members;
- Aim and objectives of the proposed SIG;
- Proposed activities of the SIG;
- List of iHEA members willing to contribute to SIG activities: A basic requirement for consideration of an SIG proposal is at least 10 iHEA members expressing a willingness to participate in the SIG, preferably from different regions with at least some from high-income countries and some from low- and middle-income countries; and
- Names and brief biographies of proposed convener(s) of SIG who would take responsibility for developing the program of work and its implementation.

Proposals to establish SIGs can be submitted to ihea@healtheconomics.org at any stage, and the iHEA Board will consider proposals at regular intervals and at least every six months. If you would like to discuss your ideas for an SIG proposal, please contact the Executive Director (diane.mcintyre@healtheconomics.org). For those interested in submitting a proposal, the iHEA Board of Directors will be meeting in January 2018, so all proposals to be considered at this meeting should be submitted no later than January 5, 2018.

ISPOR

Improving healthcare decisions

ISPOR—*The Professional Society for Health Economics and Outcomes Research*

505 Lawrence Square Blvd South

Lawrenceville, NJ, USA 08648

Monday, August 6, 2018

Health Preference Research Special Interest Group

Juan Marcos Gonzalez (Chair)

Catharina (Karin) Groothuis-Oudshoorn (Chair-elect)

Greetings from the Special Interest Group (SIG) on health preference research for ISPOR – The Professional Society for Health Economics and Outcomes Research. We recently started an exciting new chapter in our group's history and wanted to share our excitement with you. After a brief pause, we have relaunched our SIG with new leadership and a great deal of enthusiasm to motivate ISPOR members to learn about and use preference-research methods.

For those of you who are not familiar with ISPOR, it is a Society that seeks to advance the science and practice of health economics and outcomes research around the world. ISPOR currently has more than 20,000 members with chapters in more than 120 countries. Members span a wide array of stakeholders that include patient representatives, researchers, industry representatives, and regulators.

As the chair-elect and current chair of the health-preference research SIG, Karin and I would like to invite you to consider getting involved. ISPOR can provide an important platform to share and disseminate the great work that IAHPR members do. Our SIG, specifically, is also looking for opportunities to convey the standards that good preference research should meet. As a member of IAHPR, your input and support would be vital in achieving this objective. The SIG also has several initiatives looking at the role of preference research in reimbursement decisions in Europe and broadening the use of individual-level preference information.

If you already are a member of ISPOR, consider joining our SIG. If you are not currently a member of ISPOR, consider attending one of ISPOR's upcoming events around the world to experience what this organization and our SIG have to offer.

See you at ISPOR!

Juan Marcos Gonzalez and Catharina (Karin) Groothuis-Oudshoorn

International Health Economics Association

Monday, July 30, 2018

Health Preference Research Special Interest Group

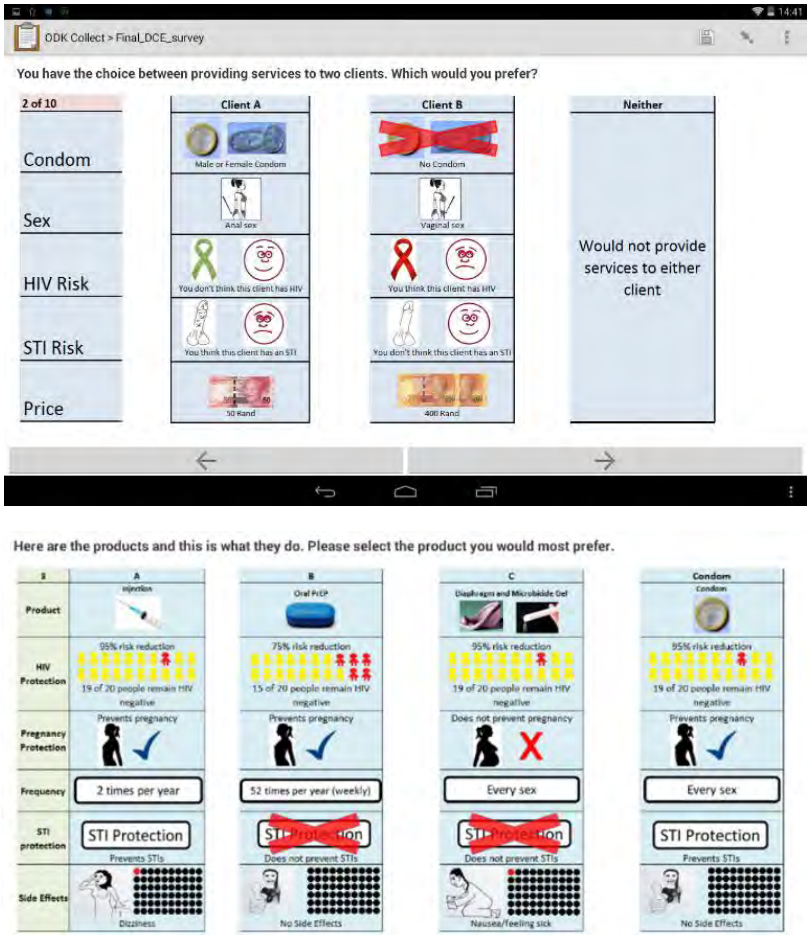
Fern Terris-Prestholt, Matt Quaife and Alec Miners

The aim of the newly formed Health Preference Research SIG is to provide an exciting and interactive forum for health preference researchers and students, including those who are new to the area, to discuss all topic related issues. For example, from methodological matters regarding the experimental design and analysis of preference evidence to the application of preference evidence (e.g., valuation of health outcomes, design of interventions for targeted uptake, parametrising uptake in economic evaluations) for regulatory, clinical and individual decision-making.

The SIG also aims to work closely with the International Academy of Health Preference Research (IAHPR), an established specialist group of HPR researchers. Follow this link for information on IAHPRs upcoming meetings (http://iahpr.org/meetings/).

The SIG's specific objectives are available here but one of the initial objectives is to produce a series of 'state of the art' webinars, which can be used as a resource when designing preference studies. The SIG is currently in the process of putting these together with the aim of having a live stream in October of this year. Join now to ensure you receive notifications regarding this series, and other SIG related information, including plans for the next iHEA conference.

Do you have work in progress and are looking for feedback? You can post issues for collegial discussion, or volunteer to give a work in progress seminar!



Taken from iHEA News - July 2018
Posted by Nicole Cork
https://www.healtheconomics.org/news/411237/iHEA-News---July-2018.htm

IAHPR
International Academy of Health Preference Research

BUSINESS SESSION

Opening, Jan Ostermann, Meeting Co-Chair
Science, Derek S. Brown, Scientific Director
Publications, Axel C. Mühlbacher, Vice Chair
Development, Benjamin M. Craig, Chair
Membership, Meenaski Bewtra, Meeting Co-Chair
Closing, Jan Ostermann, Meeting Co-Chair

OVERVIEW

OPENING

Jan Ostermann

Meeting Co-Chair

SCIENCE

Derek S. Brown

Scientific Director

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.

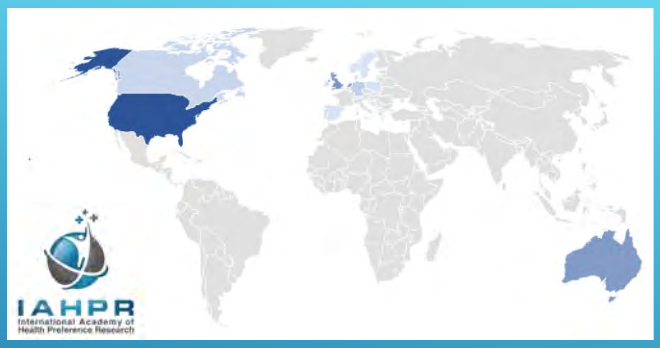
Foundation Board

Benjamin M. Craig, Chair
Axel C. Mühlbacher, Vice Chair
Emily Lancsar, Director of Outreach
Derek S. Brown, Scientific Director
Kirsten Howard, Director

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.

iahpr.org

USA	23
UK	13
Australia	12
The Netherlands	10
Germany	4
Canada	3
Ireland	2
Singapore	2
Norway	1
Poland	1
Spain	1
Sweden	1



Our faculty (38 tenured and 35 regular members in 2018) comprise an international network of multilingual, multidisciplinary researchers who contribute to the field of health preference research.

IAHPR membership is based on participation (invitation-only, rather than a dues-only membership).

- Present at a meeting → invitation to be a member
- Present two podiums → invitation to be a tenured member

iahpr.org

Deborah Street

Stephen Poteet

Welcome New Members

Elisabeth Huynh and Richard De Abreu Lourenço

In 2018, IAHPR activities have largely focused on:

1. Meetings (Hobart, Montreal)
2. Textbook
3. Registry (hpstr.org)

8th Meeting,
Hobart, Tasmania, Australia
chaired by Brendan Mulhern and Richard Norman
Symposium: *Design of Discrete Choice Experiments*

9th Meeting,
Montréal, Québec, Canada
chaired by Meenakshi Bewtra and Jan Ostermann
Symposium: *Support Tools for Preference-Sensitive Decisions*

Thank you for your participation!

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10th Meeting, Basel, Switzerland, 13-14 July 2019
chaired by **Esther de Bekker-Grob** and **Jennifer Whitty**
Workshop: *Good research practices for health preference studies* led by Axel C. Mühlbacher
Symposium: *Patient preferences in medical treatment lifecycle, Nigel Cook, Michael Drummond, Mandy Ryan*

iHEA

2019 iHEA World Congress

July 13-17, 2019 | Basel, Switzerland

Public Preferences in Screening and Prevention Uptake
This session will focus on health preference studies that examine the effect of attributes on the uptake of screening and preventive services within a community. We encourage submissions that apply rigorous experimental designs, innovative methods, and implementation strategies that improve uptake and demonstrate cultural competence, particularly in heterogeneous and underserved populations

The Use of Discrete Choice Experiments in Policy: Future Directions and Challenges
Discrete choice experiments are widely used in health economics to model preferences and to predict choice. However, their uptake in decision making has been limited to date. Reasons for this slow adoption may include risk-aversion from policy makers when considering new methodology, or concerns about the generalizability of DCEs. We encourage submissions that consider either the theoretical or practical issues with adoption, and any exemplar instances of DCE use in such settings.

IHEA
Abstract Submissions Open: Monday, September 10, 2018
Abstract Submissions Close: Monday, December 10, 2018
Abstract review results announced in March 2019.

IAHPR
Abstract Submissions Open: February 2019
Abstract Submissions Close: Monday, April 15, 2019
Abstract review results announced in early May 2019.

The 11th Meeting of the International Academy of Health Preference Research

Workshop & Symposium	Networking Dinner	Scientific Meeting
Monday, 2 December 2019 from 08:00 to 17:30	Monday, 2 December 2019 from 18:00 to 22:00	Monday, 3 December 2019 from 08:00 to 17:30

11th Meeting,
Auckland, New Zealand, 2-3 December 2019
chaired by **Richard De Abreu Lourenço** and **Elisabeth Huynh**
Workshop: *Good research practices for health preference studies* led by **Kirsten Howard** and **Emily Lancsar**
Symposium: To be determined.
Abstract Submissions Open: July 2019
Abstract Submissions Close: Monday, September 18, 2019
Abstract review results announced in mid October 2019.

Beyond empirical quantitative studies, the IAHPR scientific committee welcomes other forms of health preference research, such as:

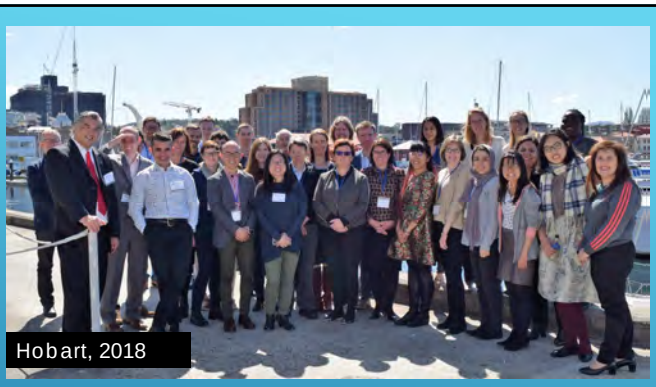
(1) novel conceptual abstracts with strong implications;

(2) the development and application of support tools for preference-sensitive decisions, such as decision aids; and

(3) methodologic comparisons, such as simulation and secondary analyses.

Pioneering extensions of the stated- and revealed-preference conceptual frameworks are encouraged (with or without empirical results).

ABSTRACT SUBMISSION GUIDELINES


Hobart, 2018

Starting in 2020:

1. **Annual,** instead of two per year
2. **Cycle** across the three regions (Europe, Asia/Pacific, North America)
3. **Extend the meeting length** by from 12 to 18 podiums, adding a half day.

The 12th Meeting will be held on October 16-18 in Chicago, Illinois, USA and chaired by **Ateesha Mohammed** and **Shelby Reed**.

Discussion on Symposium Topic

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IAHPR
International Academy of Health Preference Research

PUBLICATIONS

Axel C. Mühlbacher

Vice Chair

Chapter 1 Introduction
Chapter 2 Identification and description of attributes
Chapter 3 Preference-elicitation task
Chapter 4 Experimental design
Chapter 5 Survey instrument
Chapter 6 Data collection
Chapter 7 Analysis
Chapter 8 Interpretation and presentation
Chapter 9 Applications
Chapter 10 Advanced topics
Checklist, Worked Example, Glossary, Author Index, Subject Index

METHOD FOR HEALTH PREFERENCE RESEARCH

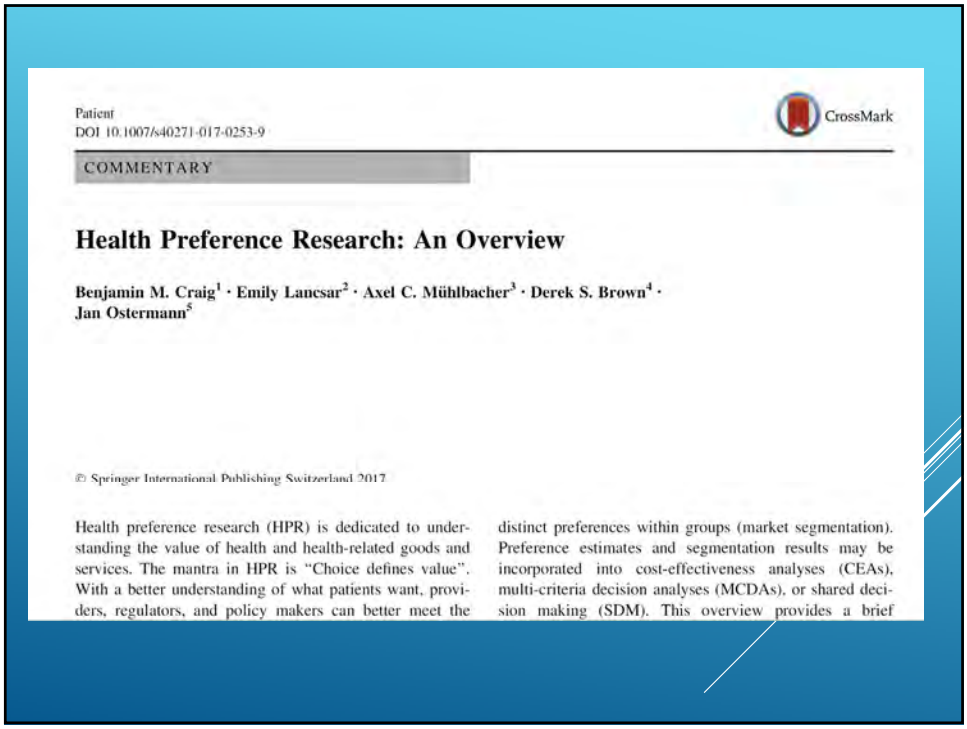
Stage 1: Writing Chapter 1 and Outlines for Chapters 2 to 9

Apr	Signed contract with Oxford University Press
May	Senior authors submit initial outlines for Ch. 2 to 9
	Authors draft Chapter 1
Jun	Co-authors review the outlines for their chapters
Aug	All authors review Ch. 1 and outlines for Ch. 2 to 9

Stage 2: Writing Chapters 2 to 9 and Editing Chapter 1

Nov15	Authors of Ch. 2 to 7 send 1000-1500 words to senior authors
	Senior authors submit revised outlines for Ch. 8 and 9
	Senior authors submit initial outlines for Ch. 10+
Dec15	Senior authors send chapters 2 to 7 to editors
	Authors of Ch. 8 to 9 send 1000-1500 words to senior authors
Jan15	Senior authors send chapters 8 to 9 to editors
Feb01	Member review Ch. 1 to 9 and final outline for Ch. 10+

Stage 3: Writing Chapter 10 and Editing Chapters 1 to 9



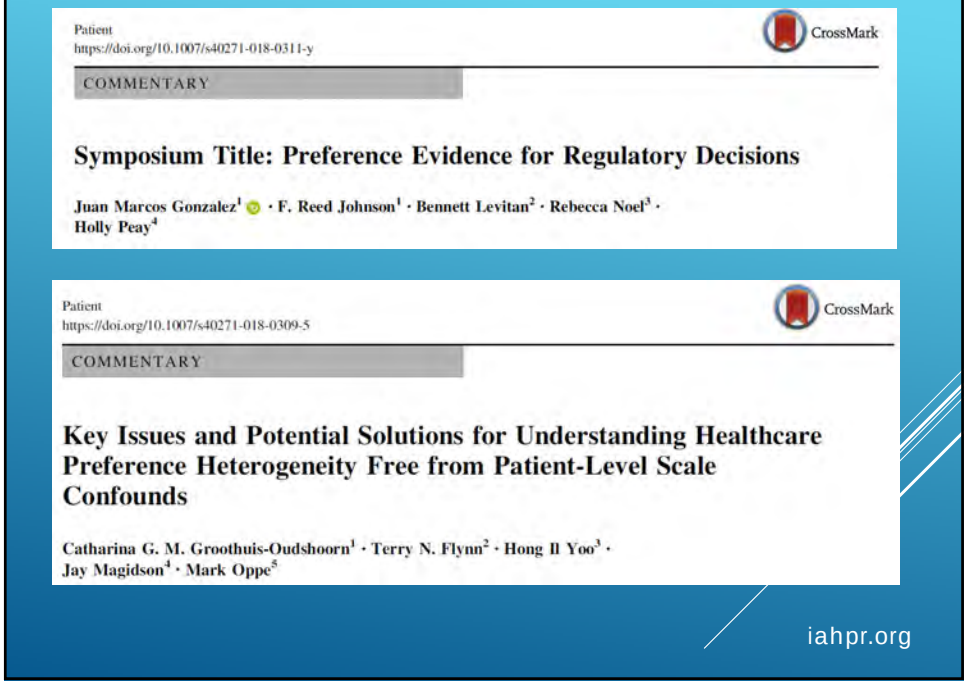
Patient
DOI 10.1007/s40271-017-0253-9

COMMENTARY

Health Preference Research: An Overview

Benjamin M. Craig[1] · Emily Lancsar[2] · Axel C. Mühlbacher[3] · Derek S. Brown[4] · Jan Ostermann[5]

Health preference research (HPR) is dedicated to understanding the value of health and health-related goods and services. The mantra in HPR is "Choice defines value". With a better understanding of what patients want, providers, regulators, and policy makers can better meet the distinct preferences within groups (market segmentation). Preference estimates and segmentation results may be incorporated into cost-effectiveness analyses (CEAs), multi-criteria decision analyses (MCDAs), or shared decision making (SDM). This overview provides a brief



Patient
https://doi.org/10.1007/s40271-018-0311-y

COMMENTARY

Symposium Title: Preference Evidence for Regulatory Decisions

Juan Marcos Gonzalez[1] · F. Reed Johnson[1] · Bennett Levitan[2] · Rebecca Noel[3] · Holly Peay[4]

Patient
https://doi.org/10.1007/s40271-018-0309-5

COMMENTARY

Key Issues and Potential Solutions for Understanding Healthcare Preference Heterogeneity Free from Patient-Level Scale Confounds

Catharina G. M. Groothuis-Oudshoorn[1] · Terry N. Flynn[2] · Hong Il Yoo[3] · Jay Magidson[4] · Mark Oppe[5]

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DEVELOPMENT

Benjamin M. Craig

Chair

IAHPR
International Academy of Health Preference Research

SUSTAINABILITY

Meenakshi Bewtra

Meeting Co-Chair

Starting in 2019, regular members:
1. Do not pay for the annual webinar,
2. Receive a 20% discount for all events
3. Are HPSTR subscribers for free

No changes to tenured memberships

Tenured members will continue to:
1. Pay for at least one event per year,
2. Attend all other events for free,
3. HPSTR contributors for free, and
4. Invited, but not required to vote, review abstracts, chair meetings, and lead other IAHPR activities.

All memberships expire three years after the last meeting attendance.

For example:
1. a new researcher who presents this year will be a member in 2019, 2020, and 2021 for free.
2. Attendance during these three years will cause their membership to renewed for three years.


Glasgow, 2017

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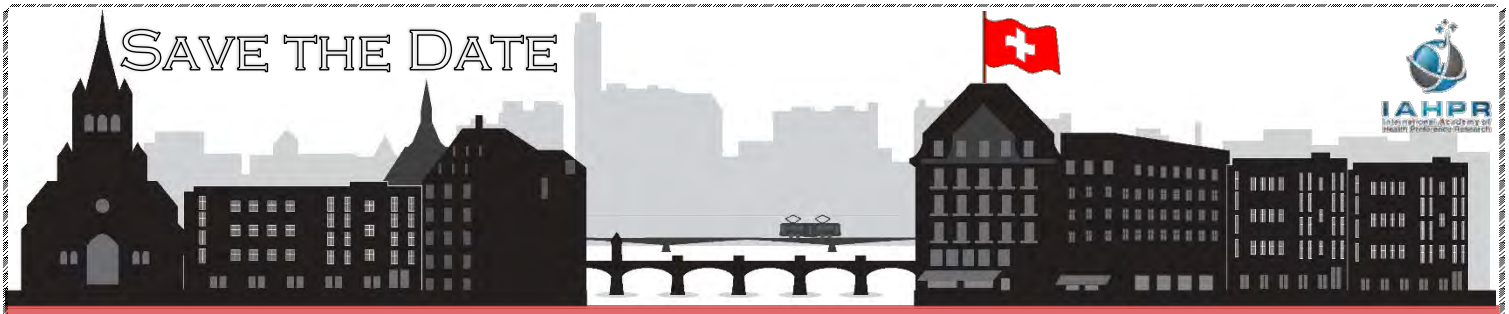
CLOSING

Jan Ostermann

Meeting Co-Chair



The 10th Meeting of the International Academy of Health Preference Research

Joint IAHPR-PREFER Workshop & Symposium

Saturday, 13 July 2019
from 08:00 to 18:00

Joint IAHPR-PREFER Networking Dinner

Saturday, 13 July 2019
from 18:00 to 22:00

IAHPR Scientific Meeting

Sunday, 14 July 2019
from 08:00 to 17:30

Chaired by **Esther W. de Bekker-Grob, PhD** and **Jennifer A. Whitty, PhD,** all events for the 10th IAHPR Meeting will be held at the Volkshaus, Basel, Switzerland as a forum to present and discuss innovative developments in health preference research.

On Saturday, 13 July 2019, the Academy and PREFER will host a joint **Workshop on Good Research Practices** led by **Axel C. Mühlbacher, PhD**. This workshop will describe the basic on how to conduct a health preference study focusing on trade-offs between risks and benefits. IAHPR members will provide examples of challenges faced during the assessment of patient preferences in health care decision making. The workshop material will build directly from the textbook under development by IAHPR members and incorporate the experiences of scientists working with PREFER.

Volkshaus Basel
Rebgasse 12-14, 4058 Basel Switzerland

After lunch, the Academy and PREFER will also host a **Symposium on "Patient preferences in medical treatment lifecycle."** This topic is of great relevance for the objectives of both, the Academy and PREFER. After the presentations by invited speakers, the panel will discuss key topics defined in advance by the co-chairs followed by a question and answer session.

After the symposium, the Academy and PREFER will host a **Networking Dinner** from 18:00 to 22:00, including a brief welcome speech from the IAHPR Foundation, which is handling all meeting arrangements. The dinner is included with registration for either the workshop/symposium, meeting or both (no guests, please).

On Sunday, 14 July 2019, the Academy will host its full-day **Scientific Meeting** including peer-reviewed podium presentations, lunch (with poster session), and a business session. The abstract submission system will open in February 2019 and close on 15 April 2019.

All are welcome to register for the workshop ($175 USD for students; $350 USD for non-students), for the symposium ($125 USD for students; $250 USD for non-students), or for the meeting ($175 USD for students; $350 USD for non-students). All registrants are invited to attend the networking dinner (no guests please). Attendees who register for a second or third events get a discount on each subsequent event ($50 USD for students; $100 USD for non-students). For example, early registration for all three events is $375 USD for students and $750 USD for non-students. Early registration will open in early May and close on 30 May 2019. Afterwards, fees double. Attendance is limited.

For more information, visit www.iahpr.org or email contact@iahpr.org

DRAFT PROGRAM

Joint IAHPR-PREFER Workshop, Saturday, 13 July 2019 from 8:00 to 12:00

Good Research Practices in Health Preference Research, **Axel C. Mühlbacher** [α]

8:00-8:15 **Arrival and Light Breakfast**

8:15-9:45 **Session 1**

9:45-10:00 **Coffee Break**

10:00-12:00 **Session 2**

12:00-13:00 **Workshop Lunch** (Workshop attendees only)

Joint IAHPR-PREFER Symposium, Saturday, 13 July 2019 from 13:00 to 17:30

13:00-13:10 **Welcome**

Meeting Chairs: **Esther W. de Bekker-Grob**[α] and **Jennifer A. Whitty** [α]

13:10-14:40 **Session 1**

Patient preference studies to inform decision-making early in the product lifecycle: industry experiences, Nigel Cook
Should health technology assessments be more patient-centric? If so, how? Michael Drummond
TBD – University of Aberdeen, Mandy Ryan[α]

14:40-15:00 **Coffee Break**

15:00-16:00 **Session 2**

TBD
TBD

16:00-17:30 **Session 3 – Panel Discussion** (Topics to be distributed in advance)

The panel includes the five symposium speakers as well as a patient advocate, Rocco Falchetto

17:30-18:00 **Concluding Remarks**

Joint IAHPR-PREFER Networking Dinner, Saturday, 13 October 2018 from 18:00 to 22:00

IAHPR Scientific Meeting, Saturday, 13 October 2018 from 08:00 to 17:30

8:00-8:15 **Arrival and Light Breakfast**

8:15-8:45 **Welcome and Acknowledgement of Sponsors**

Meeting Chairs: **Esther W. de Bekker-Grob**[α] and **Jennifer A. Whitty** [α]

8:45-10:15 **Session 1** (four podium presentations)

10:15-10:30 **Coffee Break**

10:30-11:15 **Session 2** (two podium presentations)

11:15-12:30 **Elevator Talks** (up to eight elevator talks)

12:30-13:30 **Lunch and Poster Session**

13:30-15:00 **Session 3** (Four podium presentations)

15:00-15:15 **Coffee Break**

15:15-16:00 **Session 4** (two podium presentations)

16:00-16:15 **Concluding Remarks**

16:15-17:30 **Business Session** (All attendees are welcome)

[α] indicates an IAHPR member

Amsterdam, 2014

Brisbane, 2015

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International Academy of Health Preference Research

Hamburg, 2016

St Louis, 2015

Singapore, 2016

Welcome To

IAHPR
International Academy of Health Preference Research

Boston, 2017

Glasgow, 2017

Hobart, 2018

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International Academy of Health Preference Research