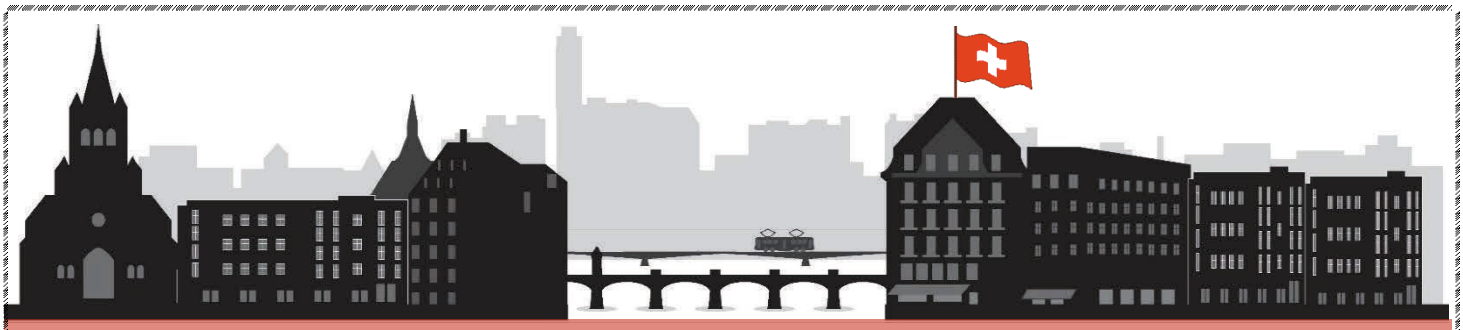

# The 10th Meeting of the International Academy of Health Preference Research

## 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 18:00

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 product 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.

**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. In 2019, the Academy had 90 members (44 tenured and 46 regular). Any researcher can join by presenting at a meeting; however, a researcher must give two podium presentations to be tenured.

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

IAHPR
International Academy of Health Preference Research

# 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**

**8:15-10:00** **Lecture**

**10:00-10:15** **Coffee Break**

**10:15-12:00** **Lecture and Hands-on exercise**

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

**Joint IAHPR-PREFER Symposium**, Saturday, 13 July 2019 from 13:00 to 18:00
Patient preferences in medical product lifecycle,
Meeting Chairs: **Esther W. de Bekker-Grob** [α] and **Jennifer A. Whitty** [α]

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

**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**
Incorporating user preferences into economic evaluations and what happens when you don't, **Fern Terris-Prestholt** [α]

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

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

Value and applicability of patient preference studies in health technology assessments, **Irina Cleemput**
Advancing Structured Regulatory Benefit-Risk Assessment, **Hans Hillege**

**16:00-17:30** **Session 3 – Panel Discussion**

A panel, including the five speakers and a patient advocate, **Rocco Falchetto**, will discuss the following topics:

1. Do you think that patient preference information in regulatory benefit-risk assessments, marketing authorisation, or reimbursement/HTA decision-making lead to higher quality decisions and increased public acceptance of decisions regarding allocation of healthcare resources?
2. To date, successful integration of patient preference information into the medical product lifecycle has been slow, unsystematic, or very limited. What should - in your opinion - happen first to reach successful integration?
3. Which preference methods do you think are most promising or acceptable to be used in regulatory benefit-risk assessments, marketing authorisation, or reimbursement/HTA decision-making and why?
4. At what point in the medical product lifecycle is patient preference information most useful, and for what purpose?
5. Is there a role for use of preference information elicited from people other than patients (e.g. carers, professionals, or the general public) to inform the medical product lifecycle? If so, how might this information be used?
6. How might patient preference information best be elicited from patients? For example, is it acceptable (or even preferable) to elicit information alongside clinical trials? If so, at the start when patients are naïve to the product, or at the end? Or should preference information be elicited in an independent preference study?

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

**Joint IAHPR-PREFER Networking Dinner**, Saturday, 13 July 2019 from 18:00 to 22:00

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[α] indicates an IAHPR member

# PROGRAM

**IAHPR Scientific Meeting**, Sunday, 14 July 2019 from 08:00 to 18:00

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

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

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

**8:30-10:30** **Session 1**

Beating the Benchmarks: Using Patient Preferences to Increase the Probability of Development Success, **Bennett Levitan** [α]

Valuation space models for the analysis of choice experiments: an example in exome sequencing, **Deborah A Marshall** [α]

Preferences in Precision Medicine: Biomarker-Based Treatment to Delay Type-1 Diabetes, **Rachael L DiSantostefano** [α]

Can healthcare choice be predicted using stated preference data? **Esther de Bekker-Grob** [α]

**10:30-10:45** **Coffee Break**

**10:45-11:45** **Session 2**

Number of Halton draws required for valid random parameter estimation with discrete choice data, **Alan R Ellis**

LC vs. SALC: Choosing Between Latent Class Models of Preference Heterogeneity, **Suzana Karim**

**11:45-12:30** **Elevator Talks**

Methodological Challenges of DCEs in Health Interventions for Children and Adolescents, **Gillian R Currie**

What Is Next for Patient Preferences in Health Technology Assessment? Systematic Review of Challenges, **Samare Huls**

Comparing dementia-specific health state values between patients, carers and older Australians, **Kim-Huong Nguyen** [α]

Preferences of Women for Labor Experience under Epidural Analgesia, **Semra Ozdemir** [α]

HPSTR report on quality-adjusted life year estimates in Alzheimer's disease, **Stephen Poteet** [α]

Best Worst Scaling: for Good or for Bad but not for Both, **Vikas Soekhai** [α]

Appraising patient preference exploration and elicitation methods in the medical product lifecycle, **Chiara Whichello**

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

**13:30-15:30** **Session 3**

Benefit-risk or risk-benefit trade-offs? Another look at attribute ordering effects in DCEs, **Sebastian Heidenreich**

Preferences for exercise and nutrition programs: A menu choice stated preference task, **Emily Lancsar** [α]

An Embarrassment of Riches: What Can You Do with 10,000 Observations? **Reed Johnson** [α]

What if 0 is not equal to 0? Inter-personal utility anchoring using the worst fears, **Michał Kosma Jakubczyk** [α]

**15:30-15:45** **Coffee Break**

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

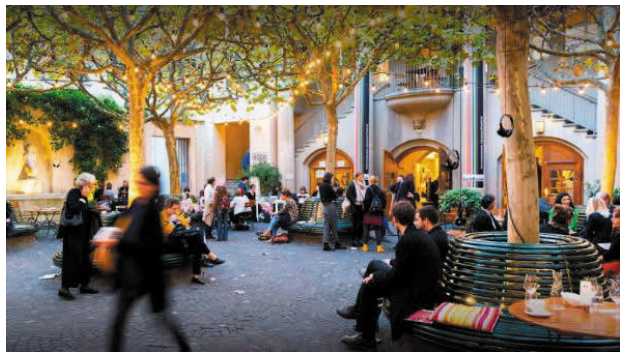
Response Quality in Discrete-Choice Experiments: An Extreme Example of Detecting Fraud, **Carol Mansfield**

Comparing online and face-to-face data quality and preferences in a health valuation study, **A. Simon Pickard** [α]

**16:45-17:00** **Concluding Remarks**

**17:00-18:00** **Business Session**

(All attendees are welcome)



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[α] indicates an IAHPR member


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# About Us

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

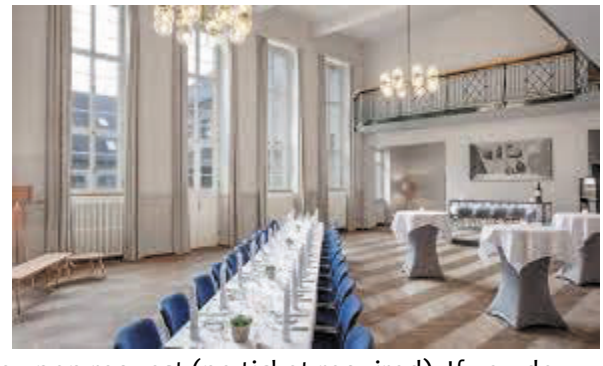
# Dining Arrangement


**Saturday, 13 July 2019**

Upon arrival (7:30) and throughout Saturday and Sunday, each table will have bottles of water (sparkling and still) and an assortment of candies. Guest may also help themselves to coffee, espresso, and tea as well as orange juice and an assortment of soda all day. At each occasion, vegetarian (v) and vegan (V) options will be available. Although the primary ingredients of all dishes do not include nuts, the Volkshaus is not a nut-free kitchen, so dishes may contain traces of nuts.

For those attending the workshop, Saturday starts with a **light breakfast buffet i**ncluding freshly baked croissants, birchermüesli (v) and a fruit basket (8:00-8:15). The **mid-morning break** (10:00-10:15) will consist of vegetable sticks and puff pastry (v). The **lunch** (12:00-12:45) includes: Chicken breast with jus, Spinach ricotta tortellini with cherry tomatoes (v), Iced gazpacho (V), Mediterranean vegetables (V), Lemon quinoa (V), multiple salads (v and V) and Seasonal yoghurt fruit mousse (v). The symposium begins after lunch. During its **afternoon break** (14:40-15:00), attendees will be served homemade cake (fruit), which is meant to tide them over to dinner.

**Networking Dinner**



All attendees are invited to a networking dinner (18:00-22:00), which will be held in the room adjacent to the symposium. Each will be greeted with a welcome glass of prosecco and serenaded by a solo guitarist. Guests will also receive two tickets for wine and beer, which includes Laus Blanco (Bodegas Laus Chardonnay, Somontano ESP), Papale di Manduria (Varvaglione Primitivo, Manduria IT), and Warteck Pic (Pilsner beer, Switzerland). 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 **aperitif selections** will be served promptly (18:15), including: Homemade puff and salty pastry, Cones filled with ratatouille mousse (V), Classical beef tartar, Shrimp cocktail, and Bruschetta (V).

The **main courses** of the chef's selection menu (19:00) include: Zurich ragout (veal), Fried fillet of pike-perch on cream sauerkraut, Röstigaletten (Swiss hash browns, v), Penne with fresh vegetables and tomato sugo (v), and Grain risotto with green asparagus and mushrooms (V, lactose free).

The **dessert table** will offer a wide variety of tempting dishes, such as: Five sweets (chocolate) from the Volkshaus Pâtissier, Two-coloured toberlone mousse (v), Caramel heads with cream (v), Panna cotta, Seasonal fruit salad (V), and Volkshaus brownie (v). Although the dinner ends at 22:00, the bar at the Volkshaus will be open until midnight.

**Sunday, 13 July 2019**

For those attending the scientific meeting, Sunday also starts with a **light breakfast buffet i**ncluding freshly baked croissants, birchermüesli and a fruit basket (8:00-8:15). The **mid-morning break** (10:00-10:15) will consist of Sbrienz cheese and chips. The **lunch menu** (12:00-12:45) includes: Cold cucumber yoghurt soup (v), Multiple salads (v and V), Beef stroganoff, Herb rice (V), Roasted vegetables (V), Fried rice with egg (v), Curd mousse with berries. During the **afternoon break** (14:40-15:00), attendees will be served chocolate cake

Patient
https://doi.org/10.1007/s40271-019-00368-9




## 10th Meeting "International Academy of Health Preference Research" Basel, Switzerland, 13–14 July, 2019

# ABSTRACTS

# 10th Meeting International Academy of Health Preference Research Basel, Switzerland 13–14 July, 2019

Published online: 18 June 2019


# 10TH MEETING OF THE INTERNATIONAL ACADEMY OF HEALTH PREFERENCE RESEARCH

**Axel C. Mühlbacher**

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.

The 10th Meeting of the International Academy of Health Preference Research will be held on Saturday and Sunday, 13–14 July 2019 at the Volkshaus in Basel, Switzerland. Chaired by Esther W. de Bekker-Grob and Jennifer A. Whitty and hosted by Axel C. Mühlbacher, its activities include a workshop, a symposium, a networking dinner, and a scientific meeting.

On 13 July 2019, the Academy and Patient Preferences in Benefit and Risk Assessments during the Treatment Life Cycle (PREFER) will host a joint morning workshop on "Good research practices for health preference studies," led by Axel C. Mühlbacher. 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, incorporating the experiences of scientists working with PREFER.

After lunch, the Academy and PREFER will host a joint afternoon symposium on "Patient preferences in medical treatment lifecycle." This topic is of high relevance for the objectives of both the Academy and PREFER. After the presentations by invited speakers, the panel will discuss critical topics defined in advance by the co-chairs, followed by a question and answer session. The symposium discussion will be summarized for publication in *The Patient*, an official journal of the IAHPR. After the symposium, the Academy and PREFER will host a joint networking dinner.

Starting at 8:00 on Sunday, 14 July 2019, the Academy will host the scientific meeting, including twelve podium presentations, lunch (with a poster session), and a business session. Twenty-seven abstracts were submitted for this meeting. Each was blinded then rated by 38 of the 44 tenured members of the Academy. The twelve abstracts with the highest rating were invited for podium presentation and are listed chronologically.

## Disclaimer

IAHPR in general requests that a high standard of science is followed concerning publications and presentations at all its workshops, symposia and meetings. However, IAHPR as a whole or its Foundation, or its members, do not take any responsibility for the completeness or correctness of data or references given by authors in publications and presentations at IAHPR events.

It is not within the remit of IAHPR or its Foundation, in particular, to seek clarification or detailed information from authors about data in submitted abstracts. Moreover, it is not within the scope of IAHPR and its committees to monitor compliance with any legal obligations, e.g., reporting requirements or regulatory actions.

## Beating the Benchmarks: Using Patient Preferences to Increase the Probability of Development Success

B. S. Levitan[1], E. G. Katz[1], R. L. DiSantostefano[2], J. C. Yang[3], A. O. Fairchild[3], S. D. Reed[3], F. R. Johnson[3]

[1]*Epidemiology, Janssen R&D, Titusville, NJ, USA;*
[2]*Epidemiology, Janssen R&D, Raritan, NJ, USA;*
[3]*Duke Clinical Research Institute, Duke University, USA*

**Background:** Drugs in development have notoriously low benchmark probabilities to reach the market. A key step in navigating these low probabilities is defining strategic requirements for development success. An industry strategy document, the target product profile (TPP), specifies minimum requirements for efficacy, safety, tolerability, formulation, dosing and other drug properties. If the TPP goals are met, development proceeds. If not, the compound strategy is reconsidered, forecasts are revised, and development may be halted.
**Methods:** While the concept of alternatives forms of success is intuitive, TPPs generally specify just one or a few options. The challenge is having a defensible means to specify equally valued alternatives. We used findings from two preference studies to show how assessing maximum-acceptable risk (MAR) for a range of benefits can generate a large family of preferentially equivalent alternatives: (1) a preference study that assessed the MAR of sudden death or disabling stroke in exchange for delaying the onset of Alzheimer's disease. (2) A preference study in treatment-resistant depression (TRD) that estimated the MAR of permanent memory/cognitive and bladder problems for improvements in depression.
**Results:** In the Alzheimer's study, for 1-year delayed onset, participants would accept 5% chance of disabling stroke. For 2 years delay, 11%. For 3 years, 17%. In the TRD study, we calculated joint probabilities of memory/cognitive problems and bladder problems that would be acceptable for different levels of benefit. For improvement from moderate to mild depression, patients would accept joint (memory/cognitive, bladder) MARs of (1.9%, 0), (1%, 1.3%), (0, 2.7%) and many other combinations. For improvement from severe to mild depression, the joint MARs are higher and include (5.1%, 0), (3%, 3%) and (0, $> 5\%$).
**Conclusions:** Preference studies can give a large family of TPP trade-offs equally valued by patients and with similar market share. These define alternative paths for development success that can "beat the benchmarks" and increase the probability of development success.

## Valuation space models for the analysis of choice experiments: an example in exome sequencing

D. A. Marshall[1], K. V. MacDonald[1], S. Heidenreich[2], K. M. Boycott[3]

[1]*University of Calgary, Calgary, Alberta, Canada;*
[2]*Health Economics Research Unit, University of Aberdeen, Aberdeen, Scotland; Evidera, Inc., London, UK;*
[3]*Children's Hospital of Eastern Ontario Research Institute, University of Ottawa, Ottawa, Ontario, Canada*

**Background:** Mixed logit models for the analysis of health care choices usually estimate random marginal utilities. Marginal rates of substitutions (MRSs) are subsequently obtained as the ratio of two coefficients. To ensure that obtained distributions of MRSs have finite moments, the distribution of the numéraire needs to be fixed or bounded. However, resulting ratio distributions can be highly skewed, behaviourally implausible or difficult to interpret. Previous research suggests overcoming these limitations by directly estimating distributions of MRSs. Using a discrete choice experiment (DCE) estimating the added value of exome sequencing (ES) over standard diagnostic tests for rare diseases, we illustrate the usefulness of such valuation space models.
**Methods:** We administered a DCE with six attributes (diagnostic test, chance of diagnosis, negative impact of diagnosis, positive impact of diagnosis, out of pocket test cost and time to diagnosis) to parents of children with rare diseases. Valuation-space models were used to obtain three MRSs: willingness to pay, willingness to wait for test results and minimum acceptable chance of a diagnosis.
**Results:** 89% of 319 respondents reported their child had genetic testing, 66% received a diagnosis and 26% reported that their child had been offered ES. For most attributes, preferences varied significantly between respondents. The valuation-space model results estimated that parents would be willing to pay CAD$6590 (SD: $5050), wait 5.2 years (SD 3.98 years) to obtain a diagnostic test result, or accept a reduction of 3.1% (SD 2.44%) in the chance of receiving a diagnosis for ES testing compared to operative procedures.
**Conclusions:** While random marginal utilities can account for unobservable heterogeneity in preferences, distributions or MRSs can be highly skewed and may require unreasonable assumptions to ensure model identification. Valuation-space models can meaningfully address this problem by directly estimating the distributions of MRSs.

## Preferences in Precision Medicine: Biomarker-Based Treatment to Delay Type-1 Diabetes

R. DiSantostefano[1], J. Sutphin[2], K. Gallaher[2], C. Mansfield[2]

[1]*Janssen R&D, LLC, Titusville, NJ, USA;*
[2]*RTI Health Solutions, RTP, NC*

**Background:** Biomarker screening and associated treatment decisions to prevent or delay disease involve layers of uncertainty and complexity, and they are increasingly utilized in personalized and preventive medicine. We evaluated parent preferences for hypothetical treatments that delay the onset of T1D insulin dependence in children to inform medicines development.
**Methods:** A discrete choice experiment survey using an online research panel assessed the preferences of US parents told to assume one of their children ($< 18$ years) would become insulin dependent with T1D within 2 years based on a biomarker test. The online web-based panel ($n = 1501$) included parents with ($n = 600$) and without ($n = 901$) a child with T1D. Respondents were offered a series of eight choices between two hypothetical treatments that would delay T1D or an opt out (monitoring only). Treatments were defined by six attributes with varying levels of benefits and harms. Random Parameter Logit (RPL) modeling was used to assess preferences, stratified by already having/not having a child with T1D. Latent class analysis (LCA) was used to explore heterogeneity.
**Results:** Most parents chose a treatment (2% always chose the opt out). LCA results yielded 5 classes where parents focused mostly on (1) delaying T1D insulin dependence, (2) reducing long-term risk of T1D complications, (3) avoiding serious infection, (4) monitoring only (opt out), (5) and a disordered class ($\sim 20\%$) that may have based their decision on other properties, misunderstood, and/or were task non-

attendant. Class membership was related to differences in patient characteristics, insurance status, and performance on comprehension questions.
**Conclusions:** This study identified five distinct groups whose preferences can inform development decisions for future treatments to delay T1D. The growth of precision medicine requires understanding preferences in a more complex and uncertain decision context, which may require advancements in preference methods.

## Can Healthcare Choice be Predicted Using Stated Preference Data?

E. W. de Bekker-Grob[1], B. Donkers[1], M. C. J. Bliemer[2], J. Veldwijk[1], J. D. Swait[1]

[1]*Erasmus Choice Modelling Centre, Erasmus University Rotterdam;*
[2]*Business School, University of Sydney*

**Background:** The lack of evidence about the external validity of discrete choice experiments (DCEs) is one of the barriers that inhibits greater use of DCEs in healthcare decision-making. This study examines external validity of DCE-derived preferences, unravel its determinants, and provide evidence whether healthcare choice is predictable.
**Methods:** We focused on the field of influenza vaccination and used a six-step approach: (1) a literature study, (2) expert interviews, (3) focus groups, (4) a survey including a DCE, (5) field data, and (6) in-depth interviews with respondents who showed discordance between stated preferences and actual healthcare utilization as a mean of diagnosing model mis-specification. Respondents without missing values in the survey and the actual healthcare utilization (377/499 = 76%) were included in the final analyses. Random-utility-maximization and random-regret-minimization choice processes were used to analyze the DCE data, whereas the in-depth interviews combined five scientific theories to explain discordance.
**Results:** When models took into account both scale and preference heterogeneity, real-world choices to opt for influenza vaccination were correctly predicted by DCE at an aggregate level, and almost 90% of choices were correctly predicted at an individual level. There was 13% (49/377) discordance between stated preferences and actual healthcare utilization. In-depth interviews showed that several dimensions played a role in clarifying this discordance: attitude, social support, action of planning, barriers, and intention.
**Conclusions:** Evidence was found, at least in this particular study, that DCE yields accurate predictions of real-world behavior if at least scale and preference heterogeneity are taken into account. Analysis of discordant subjects showed that we can even do better. The DCE measures an important part of preferences by focusing on attribute tradeoffs that people make in their decision to participate in a healthcare intervention. Inhibitors may be among these attributes, but it is more likely that inhibitors have to do with exogenous factors like goals, religion, phobias, and social norms. Conducting upfront work on constraints/inhibitors of the focal behavior, not just what promotes the behavior, might further improve predictive ability.

## Number of Halton Draws Required for Valid Random Parameter Estimation with Discrete Choice Data

A. Ellis[1], E. de Bekker-Grob[2], K. Howard[3], K. Thomas[4], E. Lancsar[5], M. Ryan[6], J. Rose[7]

[1]*Department of Social Work, North Carolina State University, Raleigh, USA;*
[2]*Erasmus School of Health Policy and Management, Erasmus University Rotterdam, Netherlands;*
[3]*School of Public Health, University of Sydney, Australia;*
[4]*UNC Eshelman School of Pharmacy, University of North Carolina at Chapel Hill, USA;*
[5]*Department of Health Services Research and Policy, Australian National University;*
[6]*Health Economics Research Unit, University of Aberdeen, UK;*
[7]*Business Intelligence and Data Analytics Research Centre, University of Technology Sydney, Australia*

**Background:** Mixed-logit models of discrete choice experiment (DCE) data often simulate random parameters with Halton draws. The model assumes uncorrelated random parameters with certain (often normal) distributions. Using too few draws may violate these assumptions, biasing estimates and standard errors, but guidance about number of draws is lacking. Systematic review data show that number of draws is rarely reported, highly variable, and unrelated to number of random parameters. We developed guidance about the number of Halton draws to use in these models.
**Methods:** In R, we simulated random parameters using 50 Halton sequences with 50 to 10,000 draws. We (1) plotted normality test results, (2) plotted correlations among parameters, (3) assessed bias and relative efficiency in real data, using models with 5, 10, and 15 random parameters and 250 to 20,000 draws, and (4) evaluated current practice by overlaying plots with data on modeling practices from 40 DCEs.
**Results:** Univariate normality: With 500 draws and 10 random parameters, or 1000 and 12, one random parameter departed from normality. With 500 draws and 17 random parameters, or 1000 and 22, half departed from normality. Multivariate normality: With $\geq 7$ random parameters, the Henze–Zirkler p-value decreased. With 11, keeping $p > 0.05$ required 4000 draws. Based on actual modeling practices, 16/40 recently published DCEs (40%) likely used insufficient draws for multivariate normality. Correlations among random parameters: Keeping correlations $< 0.2$ required 250 draws when there were 10–15 random parameters and 1000 draws when there were 22 random parameters. Based on actual modeling practices, 5/40 recent DCEs (13%) likely had correlations $> 0.1$ and 2/40 (5%) likely had correlations $> 0.2$, violating model assumptions. Real data: Models with more random parameters and fewer draws yielded bias and incorrect standard errors. With 15 random parameters, all estimates were unstable.
**Conclusions:** Stable mixed-logit estimation requires $< 10$ random parameters and $> 1000$ draws. Among 40 recent DCEs, 14 (35%) met both conditions. Future studies should develop specific guidelines and explore alternative methods. Meanwhile, number of draws should increase with number of random parameters, exceed customary levels, and be reported. Analysts should use sufficient draws for all analyses, then use more draws to verify final results. Insufficient draws may bias estimates, standard errors, and healthcare decisions.

## LC vs. SALC: Choosing Between Latent Class Models of Preference Heterogeneity

S. Karim[1], B. M. Craig[1], S. Poteet[1]

[1]*University of South Florida*

**Background:** In choice modeling, the existence of heterogeneity in structural preferences (i.e., trade-offs) and in variance (scale) (Groothuis-Oudshoorn et al. 2018) creates a dilemma for preference researchers: latent class (LC) or scale-adjusted latent class (SALC)? LC models create classes mixing both forms simultaneously, and SALC models separate them into two class types (trade-off and scale). The objective of this paper is to examine the performance of the LC and SALC models using a case example, the demand for health insurance plans.
**Methods:** The analysis included five sets of variables: paired comparison responses, plan attributes, respondent characteristics, current plan characteristics, and behavioral characteristics. The LC model identified its classes using all three characteristics, and the SALC model identified the trade-off classes using respondent and plan characteristics and the scale classes using respondent and behavioral characteristics. All models were estimated using Latent Gold (Magidson 2019). The optimal number of classes was set using the Bayesian information criterion (BIC).
**Results:** Analyzing the different LC and SALC models, the dilemma is between the LC with 3 classes (BIC 58136) and the SALC with 2 trade-offs/2 scales (58043). The two of the LC classes look similar, except one of has mis-ordered levels and smaller parameters. Respondents with less education, finished in less than 10 min, were more likely to belong to the class with the mis-ordered parameters. The SALC results clearly showed the distinction of between the two trade-off classes and between the two scale classes. Lastly, we compared the LC and SALC classes and found that the second trade-off class of the SALC looks like the merger of the two LC classes, except without the mis-ordered, small parameters.
**Conclusions:** The study demonstrates a case where the SALC model greatly improved the interpretation of preference heterogeneity (both forms). Future studies may attempt to incorporate respondent education and survey duration into their SALC models.
**References:**

Groothuis-Oudshoorn et al. Key issues and potential solutions for understanding healthcare preference heterogeneity free from patient-level scale confounds. Patient. 2018;11(5):466–6.
Magidson J. Latent gold. Belmont: Statistical Innovations; 2019.

## Benefit–Risk or Risk–Benefit Trade-offs? Another Look at Attribute Ordering Effects in DCEs

S. Heidenreich[1,2], A. Beyer[3], B. Flamion[4], M. Ross[1], J. Seo[1], K. Marsh[1]

[1]*Evidera Inc, London;*
[2]*University of Aberdeen;*
[3]*Innovus Consulting, London;*
[4]*Idorsia Pharmaceuticals Ltd*

**Background:** Discrete choice experiments (DCEs) are increasingly used for health care valuation. Policy makers (i.e. regulators and payers) have signaled their interest in exploring the use of patient preference data from DCEs in benefit-risk assessments. Using DCEs for policy making raises questions about the effect of design aspects on collected data. We use a pilot DCE, which will be integrated into a Phase 3 trial evaluating a new insomnia treatment, to explore the effect of attribute ordering on data quality indicators and statistical error variance. Only few studies previously assessed the effect of attribute ordering in DCEs and none within a benefit-risk context.
**Methods:** Respondents (N = 200) were randomized between three attribute orderings: (1) random; (2) benefits presented before risks; and (3) risks presented before benefits. Respondents were asked to complete 12 choices between unlabeled treatments and were given an opt-out option. Data quality and validity assessments included a dominance test, a preference stability test, numeracy scores, health literacy scores, and choice certainty. The effect of attribute ordering on error variance was assessed in a random effects model with design specific constants and scale heterogeneity.
**Results:** While we found no significant difference in observable data quality and internal validity measures, attribute ordering had a significant effect on the error variance. This suggests that attribute ordering may affect how respondents completed or interpreted the DCE. The error variance decreased significantly with deterministic ordering, compared to random attribute presentation. Error variance increased with the variability of stated choice certainty, health literacy, and numeracy.
**Conclusions:** Future applications of DCE should explore the implication of presentation order during instrument development. Future methods work should assess the effect of attribute ordering on policy advice and on respondents' decision-making process. Funding This study was funded by Idorsia Pharmaceuticals Ltd.

## Preferences for Exercise and Nutrition Programs: A Menu Choice Stated Preference Task

E. Lancsar[1], E. Huynh[1], J. Swait[2], J. Ride[3]

[1]*ANU;*
[2]*Erasmus;*
[3]*University of Melbourne*

**Background:** DCEs typically elicit a single choice from presented options. However, health programs/services often can or must be combined in bundles (e.g. bundling private health insurance; packaging of care coordination). We present an adaption to standard DCEs to allow for synergies between programs, to appropriately measure demand and improve external validity of the task. Our contribution is two-fold: (1) methodologically, we present a menu-based experiment to explore bundling in the context of nutrition and exercise programs; (2) econometrically, we analyse the menu-based data using an extension of the choice set generation model (GenL) proposed by Swait (2001) to account for the potential for individuals to engage in choice set formation.
**Methods:** In an online menu-based experiment, respondents were presented with three programs: a nutrition program, an exercise program and their current status quo. Respondents could choose: the nutrition program (N); the exercise program (E); both nutrition and exercise programs (C); or their status quo (S). Programs were described by cost, average weight loss, program duration and incentives, plus exercise and nutrition program-specific attributes. MNL and GenL models were compared.
**Results:** A nationally representative sample of 333 Australians completed the survey. Overall, the best GenL model performed better than the MNL ($Chi^2 = 58.99$, 5 df, $p < 0.001$). The MNL incorrectly assumes 100% weighting on the full choice set {N, E, C, S}, which accounted for only 39% of the choice set probabilities on average across the sample in the GenL. Consideration of bundling nutrition and exercise programs jointly

accounted for 69% ($p < 0.001$) of choice set probabilities on average across the sample.
**Conclusions:** We provide a template for adapting DCEs and their analysis to capture bundling options using the case study of exercise and nutrition, where programs are potentially complementary in achieving the desired goal of improving health.

## An Embarrassment of Riches: What Can You Do with 10,000 Observations?

F. R. Johnson[1], J. M. Gonzalez[1], J. C. Yang[1], J. Weatherall[2], S. Kymes[2]

[1]*Department of Population Health Sciences, Duke University;*
[2]*Lundbeck*

**Background:** The value of health spending depends on the public's willingness to pay higher taxes or reduce non-health program expenditures. Heterogeneity in preferences for taxes and programs raises questions about how to identify policy-relevant health-expenditure values. Health-policy questions also may require larger samples than commonly found in the discrete-choice experiment (DCE) health literature to inform priority-setting decisions.
**Objective:** To apply latent-class analysis using a very large data set to account for a large number of location-specific preference correlates.
**Methods:** 10,000 US adults completed an online DCE survey. Respondents answered 5 3-alternative trade-off questions consisting of status quo and two budget alternatives. Each budget profile included a mental-health program plus 2 programs randomly selected for each respondent from 4 programs: food safety, disaster relief, unemployment, and motor-vehicle safety. Benefits were scaled proportional to state population sizes. Modeling included split-sample, conditional and random-parameters logit, and various latent-class specifications, including predetermined and unconditional class assignments, with and without random parameters, with and without scale adjustments, with and without covariates, and with and without attribute-covariate interactions.
**Results:** Aggregate, split-sample, and latent-class analysis with predetermined-classes by state size yielded highly significant, but disordered, effect-coded coefficients and implausible value estimates. Unconditional latent-class models explained the implausible aggregate estimates as the result of averaging highly heterogenous group preferences. Plausible latent classes included groups who rejected taxation for any purpose (21% of the sample), who approved taxation for any purpose (14%), who had well-defined priorities among programs and were: highly sensitive to (24%), ignored (21%), or less sensitive to tax increases (20%). Only the latter group passed a scope test on tax levels.
**Conclusions:** A rare opportunity to analyze a very large DCE dataset offered numerous options for well-powered hypothesis tests but also presented challenges in how to interpret and aggregate dissimilar preferences to support decision making.

## What if 0 is Not Equal to 0? Inter-personal Utility Anchoring Using the Worst Fears

M. K. Jakubczyk[1], D. Golicki[2]

[1]*SGH Warsaw School of Economics;*
[2]*Medical University of Warsaw*

Our worst fears differ. Some people dread death while others are horrified of pain. Utilities can be rescaled within any individual but the interpersonal comparisons are questionable. Still, when compiling valuations by multiple respondents the utility of dead is assumed identical across individuals: u(dead) = 0. We motivate another approach: we assume the difference between the worst health state (as defined by EQ-5D-5L plus dead) and the best one (11111), i.e. the maximal possible improvement, is equal between individuals. Then the disutilities of dimensions/levels/dead are estimated in such range. The resulting population means are rescaled, so average u(dead) = 0 for convenience. Our approach has intuitive properties. Say, one respondent thinks moving from dead to perfect health (11111, i.e. dead→11111) for a year is worth twice as much as 55555→11111, and another respondent thinks the exact opposite. Intuitively, they collectively value the improvements as equal. However, in utility terms, we would write u(55555) = − 1 and 0.5, respectively. Hence, u(55555) = − 0.25 on average, and 55555→11111 delivers larger utility gain than dead→11111. In comparison, our approach yields u(dead) = u(55555) = 0. We test our approach using Polish EQ-5D-5L data (TTO only, 1252 individuals, 11,480 observations). Being dead was strictly the worst fear in 30% of individuals, and for 63% there was a state strictly worse. For a standard approach we get the following level-5 disutilities: MO5 = 0.262, SC5 = 0.277, UA5 = 0.187, PD5 = 0.468, AD5 = 0.225, and the estimated utility u(55555) = − 0.418. Our proposed approach yields 0.222, 0.234, 0.163, 0.423, 0.202, and − 0.245, respectively. Accounting for censoring increases the spread further. The standard approach may overestimate the importance of quality of life (intuitively, a single person with very negative utilities drives the value set down). More discussion is needed on combining utility data from multiple respondents.

## Response Quality in Discrete-Choice Experiments: An Extreme Example of Detecting Fraud

C. Mansfield[1], J. Sutphin[1], K. Gallaher[1]

[1]*RTI Health Solutions*

**Background:** Data quality issues in discrete-choice experiments (DCEs) may arise from comprehension problems, inattention to the survey, and outright fraud. We conducted two DCE surveys that were found to contain fraudulent respondents, and we explored whether common methods for assessing data quality can identify fraudulent responses.

**Methods:** Two DCE surveys measuring preferences for treatment of a chronic condition included two standard approaches to identifying potential data quality issues (comprehension questions and a dominated choice). Incorrect responses may indicate a lack of respondent comprehension or inattention but do not explain why respondents answered in unexpected ways. We estimated a random-parameter logit (RPL) model with and without respondents who failed the comprehension and dominated choice questions. A latent class analysis (LCA) model was estimated, which produced multiple classes with intuitive results and classes with disordered results. Subsequently, approximately half the respondents were discovered to be fraudulent data entered by hackers. The data were reanalyzed to identify differences in the responses provided by real and fraudulent respondents.

**Results:** Data quality problems were suspected based on unusual patterns in the demographic variables (fraudulent respondents were more likely to report being male, higher income, and having the chronic condition) and $> 50\%$ of respondents failing the comprehension questions. RPL results produced disordered attributes with large confidence intervals. Dropping respondents who failed comprehension and dominated pair questions improved the RPL results marginally. In the two surveys, 23–38% of the fraudulent respondents passed the dominance and comprehension questions, compared to 51–62% of non-fraudulent respondents. In the LCA, fraudulent respondents had a high and significant probability of being in the disordered classes.

**Conclusions:** In this extreme example, patterns in the data suggested unusual data problems. The LCA analysis was reasonably successful in creating classes that distinguished between the preferences of fraudulent and non-fraudulent respondents.

## Comparing Online and Face-to-Face Data Quality and Preferences in a Health Valuation Study

R. Jiang[1], A. Mühlbacher[2], J. W. Shaw[3], T. A. Lee[1], S Walton[1], A. S. Pickard[1]

[1]*Department of Pharmacy Systems, Outcomes, and Policy, University of Illinois at Chicago College of Pharmacy, Chicago, IL, USA;* [2]*Health Economics and Healthcare Management, Hochschule Neubrandenburg, Neubrandenburg, Germany;* [3]*Patient-Reported Outcomes Assessment, Worldwide Health Economics and Outcomes Research, Bristol-Myers Squibb, Lawrenceville, NJ, USA*

**Background:** Online data collection using panels has significant cost and time efficiency advantages over traditional methods of data collection, e.g. face-to-face (F2F). However, the extent to which data quality and elicited preferences may differ between modes is not well characterized. The aim of this study was to compare preference data as elicited using the cTTO and meta-data (e.g., time spent per task, number of trade-offs made) between F2F and online US survey respondents.

**Methods:** The F2F surveys were interviewer-assisted and implemented using the EuroQol Valuation Technology (EQ-VT) with standardized EQ-5D-5L Valuation Protocol 2.0. It was modified for online self-completion with extensive input from experienced researchers. Both modes used the same EuroQol experimental design and employed the same quota sampling for age, gender, ethnicity, and race. All cTTO data were modelled using linear regression with random intercept at the respondent level (RILS). Modes of administration were compared on elicited values; trading behavior, e.g., trading within positive cTTO values only; meta-data; and value set characteristics, e.g., range of scale.

**Results:** Online respondents (n = 501) gave more values clustered at cTTO values of 0 (15.2% vs. 5.3%) and 1 (32.0% vs. 22.2%) and fewer values at $-1$ (1.0% vs. 13.7%) than F2F respondents (n = 1134). Online and F2F mean elicited cTTO values differed when compared by health state severity (misery score 15: [Online] 0.65 [F2F] 0.25; misery score 25: [Online] 0.41 [F2F] $-0.29$). Compared to F2F, more online respondents did not assign the poorest EQ-5D-5L health state (i.e. 55555) the lowest cTTO value ([Online] 41.3% [F2F] 12.2%) ($p < 0.001$). A higher proportion of online tasks were completed in 3 trade-offs or less ([Online] 15.8% [F2F] 3.7%), ($p < 0.001$). Mean time spent per task was similar ([Online] 63.3s [F2F] 66.3s). The range of scale for the F2F sample was larger than the online ([Online] 0.600 [F2F] 1.307)

**Conclusions:** Results suggest that data quality was more of an issue when collected online. Online and F2F data provided dramatically different preferences; models estimated with online data provided much smaller disutilities.

# Appraising patient preference methods for decision-making in the medical product lifecycle: An empirical comparison

Whichello C[1], Levitan B[2], Juhaeri J[3], Patadia V[3], DiSantostefano R[2], Pinto CA[4], de Bekker-Grob EW[1]

## Aims

Currently little guidance on which **patient preference assessment methods** are **most suitable** for decision-making at different stages of the medical product lifecycle (MPLC)

This study aims to:

1. **Appraise** 33 patient preference exploration and elicitation methods;
2. Identify the methods that are **most suitable** to meet decision-makers' needs in the MPLC.

## Main message

Selection of a patient preference method depends on the research question, objectives, and feasibility of the patient preference study.

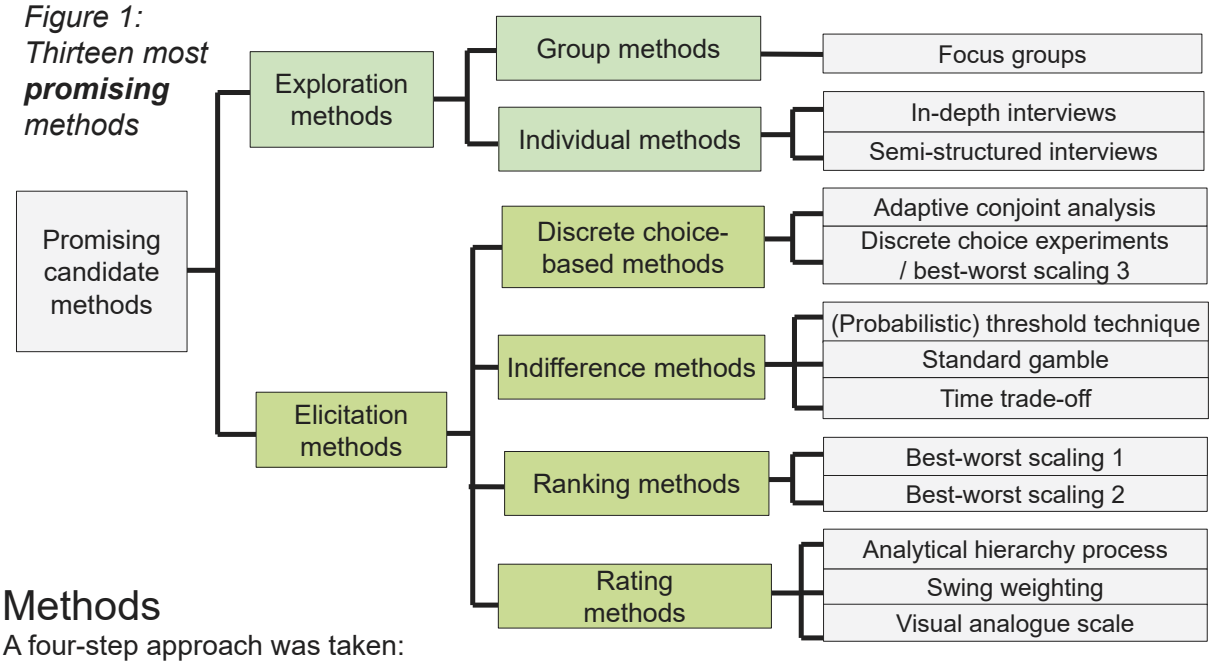
Our **empirical approach** to the comparison of methods can support decision-makers **when choosing a specific method**.

## Results

**13 preference exploration and elicitation methods** were identified across the taxonomy groups as most likely to meet decision-makers' needs (Figure 1).

Additionally, **eight other methods** that decision-makers might consider were identified, although they appeared appropriate only for some stages of the MPLC or have a low publication frequency.

*Figure 1: Thirteen most **promising** methods*




## Methods

A four-step approach was taken:

1. **Q-methodology**
   - Identified criteria to appraise the methods
   - Examined four hypothetical scenarios in the MPLC
   (n=54 HPR experts)
2. **AHP**
   - Identified numerical weights representing the relative importance for each criterion
   (n=122 HPR experts)
3. **Method performance**
   - Applied the weights, and by consulting (n=17) HPR experts and relevant literature
4. **Method comparison**
   - Comparisons made in taxonomy groups reflecting the methods' similar techniques.

*HPR = Health Preference Research*

[1]Erasmus School of Health Policy and Management & Erasmus Choice Modelling Centre, Erasmus University Rotterdam, the Netherlands, [2] Janssen R&D, United States of America, [3] Sanofi, United States of America, [4] Merck & Co, Inc, United States of America

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corresponding author: whichello@eshpm.eur.nl

# Methodological Challenges of DCEs in Health Interventions for Children and Adolescents

Gillian R. Currie, Bryanne L. Kennedy, Karen V. MacDonald, Christine Michaels-Igbokwe, Deborah A. Marshall
University of Calgary, Calgary, Alberta, Canada

## Introduction

- Task complexity and cognitive burden are important issues in the design of discrete choice experiments (DCEs).
- In designing health interventions for children and adolescents, it is important to consider their preferences to the extent that it is clinically appropriate.
  - **Unique methodological challenges** arise in applying DCE methods with this population.
- Our aim is to identify the scope of the DCE literature in child and adolescent health, and highlight the associated challenges, how they have been addressed and identify gaps in the literature.

## Methods

- We identified DCE studies examining preferences for child/adolescent health interventions in two ways:
  - Reference lists from four existing systematic reviews of the health DCE literature covering the 1990-2017 were hand searched.
  - PubMed search to capture additional studies published after the most recent systematic review (2017 to May 27, 2019).
- DCEs* were included if they examined a health intervention/service/program aimed at children/adolescents (under 19). If older age groups were also part of the study, it was included if results were reported separately for children/adolescents.
  - Data was extracted from the included studies.
- Included studies were reviewed and critically appraised.

* Following Soekhai *et al* 2019, BWS case 3 were included and BWS case 1 and 2 were excluded.

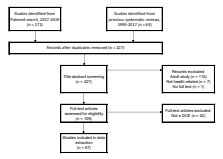


**Figure 1: Flow diagram of literature review to identify child/adolescent discrete choice experiments (DCEs)**

## Results

- 67 studies were included in the review of which 16 elicited preferences directly from children or adolescents.
- 64% of studies collected data online.
- 51% of studies were conducted in North America, with 19 studies conducted in the United States and 15 studies conducted in Canada.

Providing an opt out

- Of all studies, 36% provided an opt out. 50% of studies with child/adolescent respondents provided an opt out.
- Barber *et al.* 2019, Peyron *et al.* 2018, Burnett *et al.* 2014 raised the concern of respondents using the opt out when the choice task seems too difficult, instead of providing thoughtful responses.
  - Only Barber *et al.* 2019 did use an opt out, after a forced choice task.
- Hartmann *et al.* 2017 included an opt out, and argued that the lack of an opt out option can force children to make a choice they may not actually make.
- These considerations are not unique to the child/adolescent population.

**Looking at the 16 studies that directly elicited preferences from children and adolescents:**

Validity

- de Bekker-Grob *et al.* 2010 included a dominant choice set.
- Quaife *et al.* 2018 and Wang *et al.* 2017 repeated a choice task.
- These studies used the same methods found in adult DCEs for validity assessment.

Comprehension and cognitive capacity

- Flood *et al.* 2011 included three questions designed to test comprehension.
- Flood *et al.* 2011 suggested using age appropriate language in DCE construction is important, but didn't address how to achieve it.
- Barber *et al.* 2019 concluded, from qualitative interviews alongside the DCE, that age was not a reliable way to assess cognitive capacity for involvement in treatment decisions, because adolescents of varying ages were able to conceptualize short and long term consequences of treatment. This information was not used in the analysis, however.

DCE format to decrease cognitive burden

- Barber *et al.* 2019 reported that during pre-testing adolescents in the study voiced a desire for the ability to choose attributes within choice tasks individually or help in processing the task (such as highlighting the "better" attribute within the set). They reported using pretesting feedback to simplify choice tasks as much as possible, but this did not include highlighting the tasks.

**There has been an increase in the use of DCEs dealing with child/adolescent health between 2007-2019 (fig ). This increase is similar to the trend shown in Soekhai *et al.* 2019 for health related DCEs in general.**

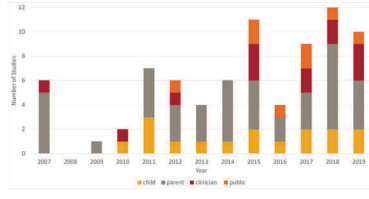
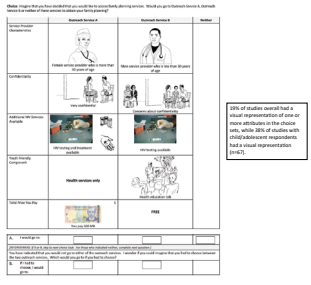



**Figure 3: Type of respondent for studies by year (n=67)**

**Few studies used visual representation of attributes in choice tasks, but a higher proportion of the studies eliciting preferences from children and adolescents directly did so.**



19% of studies overall had a visual representation of one or more attributes in the choice sets, while 38% of studies with child/adolescent respondents had a visual representation (n=67).

**Figure 5: Sample choice task presented to adolescent respondents by Michaels-Igbokwe *et al.* 2015**

**We found relatively few DCEs related to child and adolescent health, and even fewer with child/adolescent respondents. Of 67 studies, only 11 involved child/adolescent respondents.**

| Respondent Type | Number of Studies |
|---|---|
| Parent | 31 |
| Child | 11 |
| Clinician | 9 |
| Public | 6 |
| Parent and Child | 4 |
| Parent and Clinician | 3 |
| Parent and Public | 2 |
| Parent, Child, and Clinician | 1 |

**Table 1: Respondent type for 83 studies that were analyzed, including how many of the studies had that type of respondent**

**DCEs of interventions for ages 18 and under were found, but direct preferences were elicited only in children aged 8 and over**

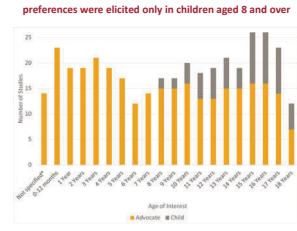



**Figure 2: Age of interest for all studies (n=67), and those with child/adolescent respondents. Note: studies could cover more than one age of interest.**
**Advocate refers to parent, public, or clinician. *specific age within 0-18 years was not specified**

**Studies covered a wide range of disease areas, with most having fewer than two studies. Among those with more than two studies. ADHD had the most studies.**

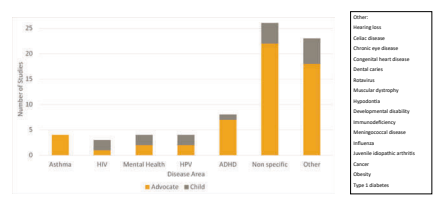



**Figure 4: Type of disease area by all child/adolescent or advocate respondents (n=67).**
**Non specific refers to studies where they did not focus on a specific disease**

## Conclusions and Future Directions

- Very few studies (n=16) elicit the preferences of the child/adolescent themselves.
  - Of those that did, few addressed methodological challenges with a child/adolescent population.
- Many of the methodological issues raised parallel those for DCEs in general, such as providing an opt out or highlighting differences in choice question profiles.
  - Further exploration of these specific to the context of the children/adolescent population is required.
- Issues we expected but were not fully addressed in the literature include:
  - The nature of joint decision making between parent and child/adolescent:
    - Five studies elicited preferences from child/adolescent and parent. None of these studies accounted for this in analysis.
  - Adaptation of design and choice task presentation for this population.
    - There were no consistent adaptations applied across studies. A small number used visual display of attributes.
  - Developmental stage and cognitive capacity to understand and complete DCE tasks.
    - Future research should explore which factors, if not age, can be used to assess cognitive capacity.
- Overall we found that DCE studies focused in child/adolescent health, and more specifically those with child/adolescent respondents, do not fully address child/adolescent specific methodological issues.
  - These unique methodological challenges require further research, and should be considered in DCE guideline and best practice development.

Contact information: Gillian Currie (email: currie@ucalgary.ca)

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UNIVERSITY OF CALGARY

# Comparing dementia specific health state values between people with dementia, caregivers and older Australians using a DCE

**Kim-Huong Nguyen[1], Brendan Mulhern[2], Julie Ratcliffe[3], Tracy Comans[1]**

1. Centre for Health Services Research, The University of Queensland; 2. CHERE, University of Technology Sydney; 3. College of Nursing and Health Sciences, Flinders University.

## Background:

- → Dementia is an expensive health problem worldwide due to an aging population. It is vitally important to assess which dementia interventions, from diagnosis to care services and treatments, offer value for money.
- → Evaluating the economic value of an intervention requires accurate estimates of costs and QALYs, the latter of which is essentially a utility-weighted length-of-life measure. Utility weights can be derived from generic or disease-specific instruments but it is essential that the instrument covers important domains for dementia quality of life, such as relationship and living situations.
- → AD5D is a dementia-specific descriptive system developed from the Alzheimer's Disease Quality of Life (QoL-AD), a well validated and widely used instrument for clinical and prospective cohort studies.
- → Involving patients and caregivers in valuing quality of life (QoL) offers a wealth of information on the lived experience of dementia. Traditionally, they have been largely excluded from preference elicitation exercises. as general population values were considered sufficient.

## Research questions:

1. Do quality of life preferences vary from one group to the next?
2. Which quality of life domains are most or least valued by each group?
3. If there are variations between groups, how do they impact on utility values?

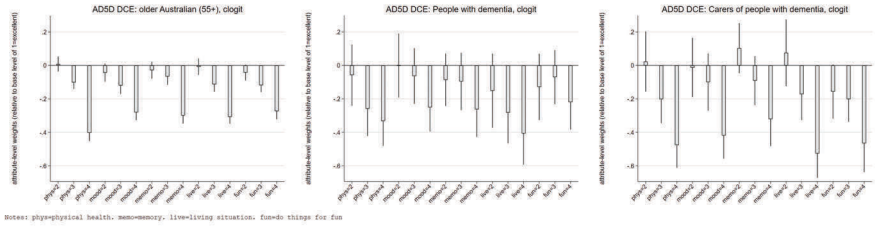
## Methods:

- → **Attributes:** Five QoL domains (physical, health, mood, memory, living situation, and ability to do fun things), each with four levels (excellent, good, fair, poor) defined by the AD5D descriptive system.
- → **Design:** An efficient design in Ngene was used to generate a discrete choice experiment incorporating survival with 200 choice sets. This consisted of 20 blocks with 10 choice sets each.
- → **Data analysis:** Multinomial logistic regressions were used to estimate the relative weights attributable to the AD5D domains. Sensitivity analyses were conducted to examine the variations of estimated parameters.

| Factor | Level | p-value | Carers | GenPops 55+ | PLWDs |
|---|---|---|---|---|---|
| N | | | 126 | 710 | 91 |
| Gender | Male | <0.001 | 31 (25.4%) | 493 (69.5%) | 57 (63.3%) |
| | Female | | 91 (74.6%) | 216 (30.5%) | 33 (36.7%) |
| Age group | <65 | <0.001 | 43 (34.1%) | 311 (43.8%) | 6 (6.6%) |
| | 65+ | | 83 (65.9%) | 399 (56.2%) | 85 (93.4%) |
| Living arrangement | Live with someone | 0.007 | 102 (81.0%) | 476 (67.0%) | 61 (67.0%) |
| | Live alone | | 24 (19.0%) | 234 (33.0%) | 30 (33.0%) |
| Education level | <10years | <0.001 | 21 (16.7%) | 43 (6.1%) | 31 (34.1%) |
| | Highschool | | 34 (28.6%) | 251 (35.4%) | 28 (30.8%) |
| | Trade | | 31 (24.6%) | 235 (33.1%) | 12 (13.2%) |
| | Uni+ | | 38 (30.2%) | 181 (25.5%) | 20 (22.0%) |
| Income by quintile | Q1: poverty line (20K) | <0.001 | 15 (15.3%) | 204 (31.3%) | 44 (51.2%) |
| | Q2: poverty to median (50K) | | 53 (54.1%) | 302 (46.3%) | 29 (33.7%) |
| | Q3: above median (80K) | | 19 (19.4%) | 82 (12.6%) | 9 (10.5%) |
| | Q4+5: above median | | 11 (11.2%) | 64 (9.8%) | 4 (4.7%) |
| Employment situation | Not working | <0.001 | 98 (77.8%) | 477 (67.2%) | 10 (11.0%) |
| | Working | | 28 (22.2%) | 233 (32.8%) | 81 (89.0%) |
| Dementia dignosis reported | No | <0.001 | 0 (0.0%) | 708 (99.7%) | 91 (100.0%) |
| | Yes | | 126 (100.0%) | 2 (0.3%) | 0 (0.0%) |

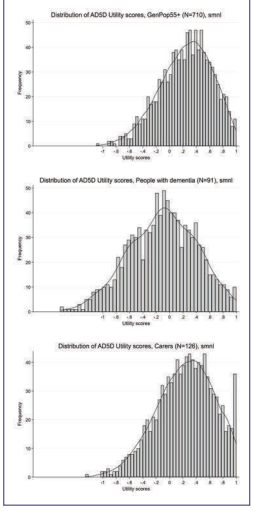
## Data collection:

- → The Australian general public undertook the survey using an online platform. Of 1,999 completed responses, we extracted a sample of older people (aged 55+, N=710).
- → People with mild to moderate dementia (N=103) and caregivers (N=131) completed the experiment via face-to-face interviews.




## Results:

- → Coefficient magnitudes vary across all three groups (and in the pooled sample) for the same estimation method, and vary across different methods for the same group. Overall, most of the preference weights given to each domain-level (poor, fair, good vs. excellent) were logically ordered. However, most of the coefficients associated with "good" were not statistically significant at 5%. And for models that accounted for sample heterogeneity, preferences were not identified among people with dementia.
- → Despite the variations across models, the ranking of most or least valued quality-of-life domain were relatively consistent for each sample. For the GenPops 55+, the largest utility decrement was for "poor physical health", followed by "poor" in other four domains. For the dementia dyads, "poor living situation" appeared to generate the largest disutilities. It appears that "poor physical health" and "poor ability to do things for fun" were also valued quite closely to `poor living situation' in the a carer group.
- → The combination of variations in preference weights across three groups, and across different method of estimation leads to a relative wide variation of utility estimates.




***Acknowledgement:*** *The AD5D project was funded by the NHMRC's Cognitive Decline Partnership Center. Views and opinions expressed here are those of the authors and do not necessarily reflect those of the funding agency or of the University of Queensland.*

# What is Next for Patient Preferences in Health Technology Assessment?*

## A Systematic Review of the Challenges

S.P.I. Huls, C.L. Whichello, N.J.A. van Exel, C.A. Uyl-de Groot, E.W. de Bekker-Grob

## Background

In HTA costs and benefits of health interventions are carefully assessed. Rather than solely using population-based QALYs as a measure of health outcome, aligning this assessment better with patient preferences can improve:

- Uptake and adherence;
- Patient satisfaction;
- Transparency;
- More informed HTA decision making.

## Problem

There is no consensus on how to integrate patient preferences in HTA in a systematic and valid manner.

## Aim

**Synthesize** the multitude of challenges raised in literature that should be addressed to advance the integration of patient preferences in HTA decision making.

## Methods

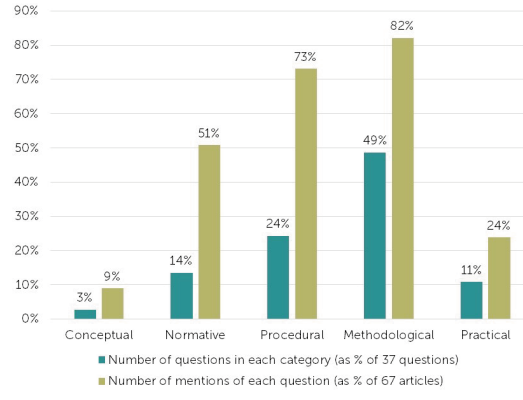
Systematic literature review

Seven databases: Embase, Medline Ovid, Web of Science, Scopus, Cochrane CENTRAL, CINAHL EBSCOhost and Google Scholar

## Results

- **Sixty-seven** out of 2,147 retrieved articles were included;
- **Thirty-seven** different research issues were identified;
- Questions were **categorized** into conceptual, normative, procedural, methodological and practical questions;
- Methodological and procedural questions were mentioned most often;
- Common **procedural issues** concerned the evaluation of the impact of preference studies and the extent to which

**Figure: Occurrence of research issues**




## Take-home message

- The debate in literature on how to integrate patient preferences in HTA in a systematic and valid manner comprises **37 research issues** that concern the integration of patient preferences in HTA;
- The majority of the issues was raised by academic authors of the articles and the articles provide **little guidance on how to address the issues**;
- **International and multi-stakeholder collaboration** is needed to advance this research agenda.

## Want to know more?

Samare Huls
huls@eshpm.eur.nl

Erasmus School of Health Policy & Management

Erasmus Choice Modelling Centre

* Article forthcoming in Value in Health

# Preferences of Women for Labor Experience under Epidural Analgesia

Semra Ozdemir[1], Chin Wen Tan[2], Drishti Baid[1], Eric Finkelstein[1], Ban Leong Sng[1,2]

[1]Duke-NUS Medical School, Singapore, [2]KK Women's and Children's Hospital, Singapore

## BACKGROUND

Childbirth is considered one of the most painful experiences, and epidural analgesia (EA) has been used to control labor pain by about 40% of the women in Singapore.

## AIMS

This study aims to develop a discrete choice experiment (DCE) to:

- assess the relative importance of control (button) over epidural dosage, chance of breakthrough pain, chance of motor block, chance of instrumental delivery and expected out-of-pocket costs for controlling labor pain via EA.
- quantify how much women are willing to pay for a novel EA method which allows having control (button) over epidural drug dosage.

## METHODS

**Setting**

The largest (public) hospital specialising in healthcare for women and children in Singapore.

**Participants**

- 163 nulliparous women, who were checked in for childbirth and had already chosen to receive EA.

**DCE Choice Tasks**

- Participants were presented with two hypothetical EA options in each choice task, and asked *"If you had only two options, which would you choose?"*
- Each option was described in terms of 5 attributes. The attributes and their corresponding levels are shown in the Table below.

***Table 1: Attributes and Levels***

| Attribute | Levels |
|---|---|
| **Control (button) over epidural dosage** | Yes (Has control)<br>No (No control) |
| **Chance of breakthrough pain (%)** | 5%<br>10%<br>20%<br>40% |
| **Chance of motor block (%)** | 4%<br>10%<br>20% |
| **Chance of instrumental delivery (%)** | 10%<br>20%<br>40% |
| **Expected out-of-pocket cost for epidural (one time)** | $ 300<br>$ 600<br>$ 1,200<br>$ 2,000 |

**Analysis**

- A D-efficient design was created in SAS and 3 blocks of 8 tasks were randomly assigned to each woman.
- A monotonicity task was also included in each survey to check whether respondents payed attention to the choice tasks. In this task, two choices were presented such that one of the alternatives was strictly better than the other alternative in all attributes.

## RESULTS

- A total of 163 women responded to the DCE survey. Among these, 36 (22%) failed the monotonicity task and were excluded from subsequent analyses.
- This large proportion can be explained by the fact that the DCE survey was administered while participants were experiencing labour pain or had given birth shortly before the survey.

**Participant's demographic profile (N=127)**

- Median age in sample was 29 years (Standard Deviation: 3.8).
- Ethnic profile: Chinese (50%), Indian (17%), Malay (16%), and Others (16%).

## RESULTS (contd.)

- The mean worst reported pain during labor at the time of the survey was 7.7 out of 10 (SD: 2.2).
- Median duration of labour was 11 hours (SD: 7.5).

**Findings from Latent Class Analysis (N=127)**

- Analyses of latent class models from 2 to 4 classes led to the adoption of a 2-class solution.
- The main concern of the first class was the risk of instrumental delivery (instrumental-delivery-averse group), and the second class was most concerned with out-of-pocket costs, followed by control over dosage (pain-control group).
- Cost was very important to both classes.
- Over half (55%) of the participants were in the instrumental-delivery-averse group, while the rest (45%) were in the pain-control group).
- Reporting a higher level of worst pain during labor was a significant predictor of being in the pain-control group ($p<0.10$).

***Figure 1: Relative Importance of Attributes by Class***

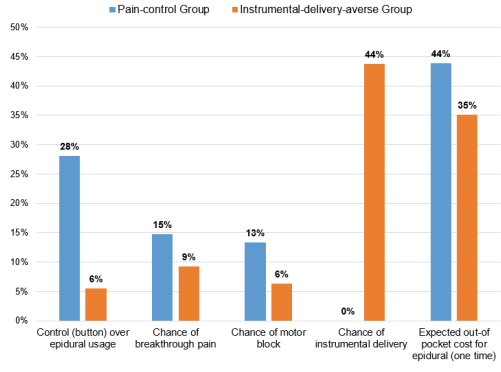



***Table 2: Willingness To Pay For Epidural Features (SGD)***

| | Instrumental delivery-averse group (55%) | Pain-control group (45%) | Full Sample (weighted) |
|---|---|---|---|
| **Control (button) over epidural dosage** | $ 269 | $ 1,089 *** | $ 637 *** |
| **Reducing chance of break-through pain from 40% to 5%** | $ 448 | $ 571 * | $ 503 *** |
| **Reducing chance of motor block from 20% to 4%** | $ 306 | $ 516 ** | $ 400 *** |
| **Reducing chance of instrumental delivery from 40% to 10%** | $ 2,119 *** | $ 0 | $ 1,142 *** |

Note: ***, **, * indicates significance at 1%, 5%, 10% levels.

- While the pain-control group was willing to pay $1,089 for having control over dosage, the instrumental-delivery-averse group was willing to pay only $269.
- On the other hand, women in the instrumental-delivery-averse group were willing to pay a significantly large amount of $2,119 for reducing the chance of instrumental delivery from 40% to 10%. In contrast, women in the pain-control group were not willing to pay for the same risk reduction.

## CONCLUSION

Women value having control over epidural drug dosage to have better pain control. However, they are also very concerned about the risk of instrumental delivery.

**CORRESPONDENCE:** Semra Ozdemir, Lien Centre for Palliative Care, Program in Health Services & Systems Research, Duke-NUS Medical School, Singapore – 169857

**Email:** semra.ozdemir@duke-nus.edu.sg

**SOURCE OF FUNDING:** National Medical Research Council (NMRC) Clinical Trials Grant 2013 (Singapore)

# HPSTR report on quality-adjusted life year estimates in Alzheimer's disease

Stephen W. Poteet[1] and Benjamin M. Craig[2]

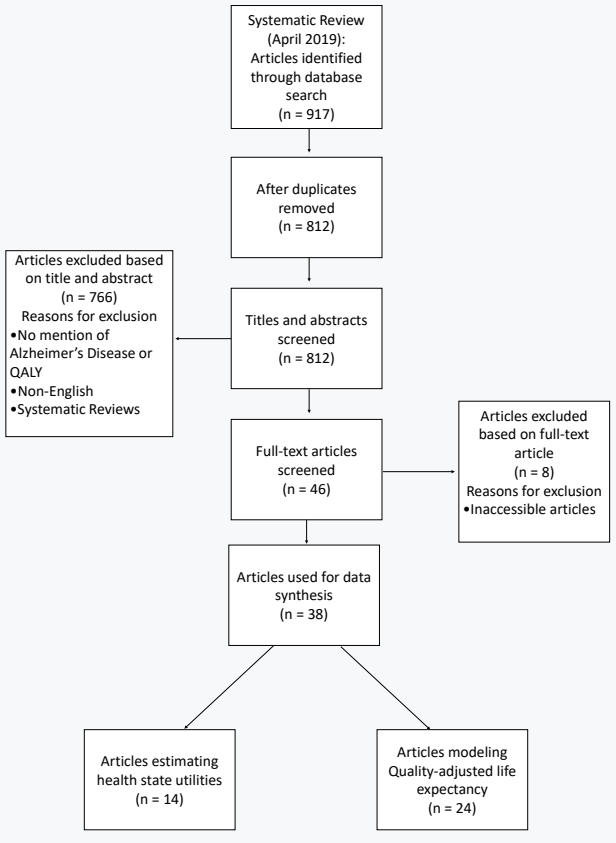
## Background

Multiple cost-utility models on Alzheimer's disease (AD) treatments have been published, but little is being reported on the sources of their preference-related parameters. The objective of this study was to identify and review quality-adjusted life-year (QALY) estimates in AD and their use in cost-effectiveness modeling studies in terms of quality and validity.

## Methods

The systematic review protocol was registered in PROSPERO. It began with a search of PubMed, HPSTR, CEA Registry, Cochrane Library, ScienceDirect, and NICE databases for research articles published between January 1998 and April 2019. Each article was appraised for methodological quality using methods adapted from ISPOR SpRUCE checklist. The QALY estimates were then synthesized into an all-inclusive table for use in decision analyses.

Figure 1: PRISMA Diagram




## Results

In total, 917 articles were identified with 38 being included in the final analysis. All QALY estimates were from 14 observational or controlled trials. Each included a health-related quality of life instrument with preference-weights.

The studies were conducted in 10 different countries. Multiple severity levels were identified (Questionable, Very Mild, Mild, Mild to Moderate, Moderate, Severe, Very Severe, Profound, Terminal, MMSE 26-30, MMSE 21-25, MMSE 10-15, and MMSE 0-9).The health-related quality of life data came multiple perspectives (patients and caregivers), sample sizes (132 to 2204) and instruments: EQ-5D-3L (8), EQ-VAS (3), HUI-2 (3), HUI-3 (2), Qol-AD (2), and EQ-5D-5L (1). As a result, the QALY estimates (n=120) ranged from 0.12 to 0.93. The quality of these studies were reviewed based off of the following criteria: transparency, type of instrument, number of citations, and method. 9 out of the 14 received an acceptable rating.

Among the studies modeling Quality-adjusted life expectancy, 24 articles had transparent estimates that were not expert opinions. We then link these analyses to their source estimates.

Table 1: Article Ratings

| Study | Year | Instrument | Number of participants | Method | Number of Citations | Quality |
|---|---|---|---|---|---|---|
| **Neumann, et al.** | 1999 | Health Utility Index Mark 2 | 679 | Observational | 163 | Acceptable |
| **Leon, et al.** | 2000 | Health Utility Index Mark 2 | 679 | Observational | 34 | Acceptable |
| **Jonsson, et al.** | 2006 | EQ-5D-3L, EQ-VAS, and QOL-AD | 272 | Observational | 143 | Acceptable |
| **Lopez-Bastida, et al.** | 2006 | EQ-5D-3L and EQ-VAS | 237 | Observational | 114 | Acceptable |
| **Rosenheck, et al.** | 2007 | CATIE-AD | 421 | Randomized controlled trial | 55 | Unacceptable |
| **Nagy, et al.** | 2011 | Health Utility Index Mark 3 | 787 | Randomized controlled trial | 17 | Unacceptable |
| **Oremus, et al.** | 2014 | EQ-5D-3L | 316 | Observational | 15 | Acceptable |
| **Sogaard, et al.** | 2014 | EQ-5D-3L | 330 | Randomized controlled trial | 13 | Unacceptable |
| **Meguro, et al.** | 2015 | EQ-5D-3L | 100 | Observational | 3 | Unacceptable |
| **Lacey, et al.** | 2015 | Health Utility Index Mark 3 and QOL-AD | 2204 | Randomized controlled trial | 12 | Acceptable |
| **Fang, et al.** | 2016 | EQ-5D-3L | 216 | Observational | 7 | Acceptable |
| **Michaud, et al.** | 2017 | Health Utility Index Mark 2 and EQ-5D-3L | 132 | Observational | 0 | Acceptable |
| **Sopina, et al.** | 2017 | EQ-5D-5L and EQ-VAS | 200 | Randomized controlled trial | 5 | Unacceptable |
| **Clare, et al.** | 2019 | DEMQOL-U and EQ-5D-3L | 427 | Randomized controlled trial | 1 | Acceptable |

## Conclusion

By linking cost-effectiveness models to the source of their QALY estimates, we gain a better understanding of their quality and validity. This report provides decision analysts with a source to guide their selection of QALY estimates for future cost-utility analyses. The final report will be made available on HPSTR along with the associated articles.

[1]University of South Florida, Tampa, Florida USA spoteet@mail.usf.edu

[2]University of South Florida, Tampa, Florida USA benjamin.craig@iahpr.org

Erasmus School of Health Policy & Management

Erasmus Choice Modelling Centre

Erasmus MC Universitair Medisch Centrum Rotterdam

Vikas Soekhai[1,2,3], Bas Donkers[1,4] and Esther de Bekker-Grob[1,2]

1 Erasmus Choice Modelling Centre, Erasmus University Rotterdam, Rotterdam, the Netherlands
2 Erasmus School of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, the Netherlands
3 Erasmus MC-Erasmus University Medical Center Rotterdam, Rotterdam, Netherlands
4 Erasmus School of Economics, Erasmus University Rotterdam, Rotterdam, the Netherlands

# Best Worst Scaling: for Good or for Bad but not for Both

## Background

- Best-worst scaling (BWS) is an increasingly popular method for preference elicitation in health and healthcare
- However, BWS still in infancy and a number of issues require further exposition
- One issue is the inclusion of dominant attributes in case 2 BWS choice tasks
- Aim: study the impact of dominant attributes in case 2 BWS experiments on parameter estimation

## Methods

- Estimation problems with dominant attributes illustrated:

1. Analytically
2. Via simulations
   → self developed code in Julia Scientific Programming
   → example with 1 positive and 3 negative attributes
   → OMEP design with 9 choice tasks
   → sample size of 1000
   → 100 simulation runs

| Attributes | Positive or negative | Attribute levels |
|---|---|---|
| Attribute 1 ($A_1^+$) | + | $A_{1,1}^+$ $A_{1,2}^+$ $A_{1,3}^+$ |
| Attribute 2 ($A_2^-$) | - | $A_{2,1}^-$ $A_{2,2}^-$ $A_{2,3}^-$ |
| Attribute 3 ($A_3^-$) | - | $A_{3,1}^-$ $A_{3,2}^-$ $A_{3,3}^-$ |
| Attribute 4 ($A_4^-$) | - | $A_{4,1}^-$ $A_{4,2}^-$ $A_{4,3}^-$ |

## Results

- In situation of dominance, assuming always selecting positive above negative attributes leads to utility specification:

$$V(A_{k,l}^+) + \varepsilon^+_{k,l} > V(A_{m,n}^-) + \varepsilon^-_{m,n},\ m \neq k$$

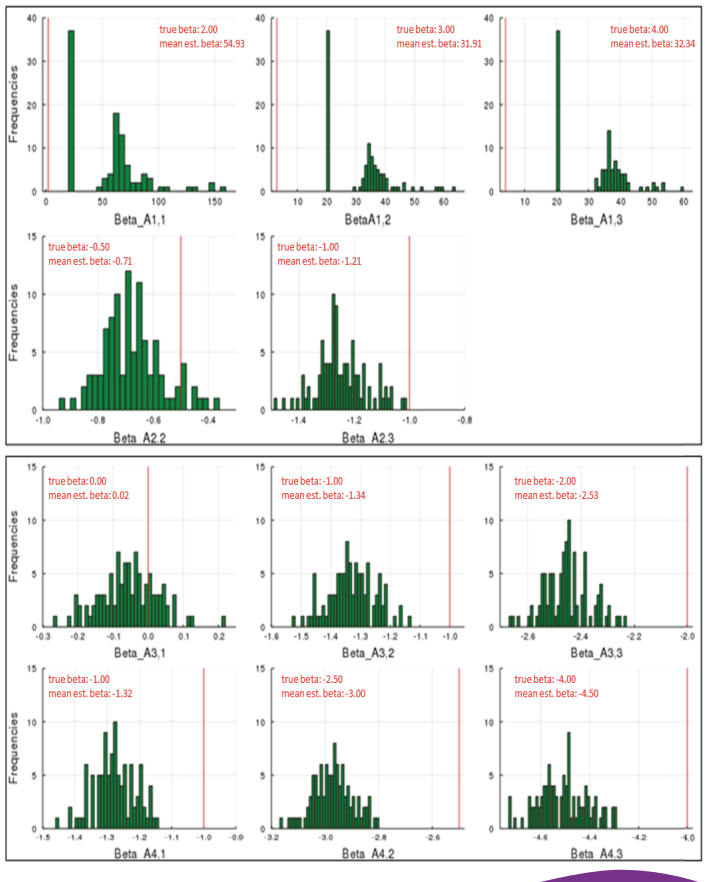
This inequality only holds, for all possible values of $\varepsilon^+_{k,l}$ and $\varepsilon^-_{m,n}$, if $V(A_{k,l}^+) - V(A_{m,n}^-)$ becomes infinitely large

- Modelling this via the multinomial logit model (MNL):

$$P(\text{best} = A_{1,1}^+) = \frac{(\exp(V(A_{1,1}^+)))}{(\exp(V(A_{1,1}^+)) + \exp(V(A_{2,2}^-)) + \exp(V(A_{3,2}^-)) + \exp(V(A_{4,1}^-)))}$$

Assuming this probability needs to be equal to one, $V(A_{1,1}^+)$ needs to be infinitely large

- Simulation results confirm analytical expectations: problems with parameter estimation for positive attributes




## Conclusions

- Mix of positive and negative attributes leads to attribute dominance in case 2 BWS
- Analytically this will lead to parameter estimation problems
- First simulation results confirm our expectations
- Case 2 BWS holds the potential of being valuable for eliciting preferences, but not for every combination of attributes

**Corresponding author**
Vikas Soekhai MSc, LLM
soekhai@eshpm.eur.nl
@ECMC_EUR

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Make it happen.

# Tenured Members in Attendance

## Meeting Co-Chairs

### Esther W. de Bekker-Grob, PhD

Dr. Esther de Bekker-Grob is an Associate Professor of Health Economics & Health Preferences at the Erasmus University (Dept Health Policy & Management) and Erasmus Medical Centre (Dept Public Health), Rotterdam, the Netherlands. Additionally, she is co-director of the interfaculty Erasmus Choice Modelling Centre (ECMC). As a response to the strong push towards personalized medicine as well as dealing with scarcity in the allocation of healthcare require, more insight into patients' preferences for medical interventions and economic evaluations is needed. Dr. Esther de Bekker-Grob's research has contributed to these issues using (1) discrete choice experiments (DCEs) - an increasing popular quantitative approach to measure patients' preferences; and (2) semi-Markov and micro simulation models to determine the cost-effectiveness for medical interventions. Her research provided valuable insights that are useful in medical decision-making. It has covered a broad range of (more than 25) medical topics in primary healthcare, clinical care as well as public health. Moreover, Dr. Esther de Bekker-Grob has addressed methodological issues focusing on designing, modelling and validation of DCEs in healthcare. She has 50 peer-reviewed publications to date (Jan 2017) in high-quality journals, and has obtained about 3.5 million euro funding for her own line of research, including prestigious personal grants. Currently, among other projects, Dr. Esther de Bekker-Grob is working on 1) PREFER (acronym for 'Patient Preferences in Benefit and Risk Assessments during the Treatment Life Cycle'); a five year project funded equally by the Innovative Medicines Initiative (Europe's largest public-private initiative aiming to speed the development of better and safer medicines for patients) and by industry as in-kind contribution, and 2) VENI project entitled 'Is patients' choice predictable?' a four year personal grant funded by The Netherlands Organisation fro Scientific Research (NWO).

Country

Netherlands

IAHPR Membership

Founding IAHPR Member

### Jennifer Anne Whitty, BPharm(Hons), GradDipClinPharm, PhD

Jennifer Whitty is Professor of Health Economics and Head of the Health Economics Group at the Norwich Medical School, Faculty of Medicine and Health Sciences, at the University of East Anglia, UK. She is also an Honorary Professor at the University of Queensland and an Adjunct Professor at Griffith University in Australia.

Jennifer is an applied health economist with a professional background in pharmacy. She leads multidisciplinary research and consultancy in health economics and decision-making. Jennifer's research focusses in particular on evaluating preferences, choices and values around health and healthcare delivery and using these preferences to inform economic evaluation and health care decision-making. She is an expert in the application of choice-¬based preference elicitation approaches such as the discrete choice experiment, and has also applied deliberative methods such as the Citizens' Jury.

Jennifer's research is supported by competitive and industry funding, including the Australian Research Council (ARC), National Health and Medical Research Council (NHMRC), and Departments of Health.

Jennifer has authored over 100 peer-reviewed journal publications and is a member of the Editorial Board for the international journals "Medical Decision Making" and "Applied Health Economics and Health Policy". She makes strong contributions to professional development in the health economics and preference elicitation fields through research student supervision and invited membership of the International Society for Pharmacoeconomics and Outcomes Research Distance Learning Faculty. She has provided direct input to Government policy-making, including consultancy to the Australian Department of Health contributing to their health technology assessment processes. Jennifer is a member of the Health Services Research Board hosted at Universities UK (HSRUK), which brings together those who produce and use evidence to improve health services.

Country

United Kingdom

IAHPR Membership

Founding IAHPR Member

## Benjamin M. Craig, PhD

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 econometric 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

## Kirsten Howard, PhD

Kirsten Howard is Professor of Health Economics in the School of Public Health at the University of Sydney. Her research focuses on methodological and applied health economics research predominantly in the areas of assessment of patient and consumer preferences using discrete choice (DCE) methods as well as in economic evaluation, and modelling. She has worked in areas as diverse as cancer treatment and screening, labour induction, aged care services, exercise interventions and falls prevention for older people, dialysis services and organ donation and allocation policy. She is also a member of the Economics Sub Committee of the Australian Government's Pharmaceutical Benefits Advisory Committee (PBAC).

Country

Australia

IAHPR Membership

Founding IAHPR Member

## Karin Groothuis-Oudshoorn, PhD

I'm a biostatistician with an interest in obtaining in a methodologically sound way of patients', physicians and other stakeholder preferences to support decisions in health care. I have worked on projects, or had an advisory role on different levels of health care decision making, including the individual patient level, evaluation of health care services, benefits and risks assessment of drugs or devices and reimbursement of drugs. My expertise is the design, analysis and interpretation of preference studies, multi-criteria decision analysis studies.
Additionally, I have more than 18 years of experience as a certified biostatistician in health services research on diverse applications in the biomedical field. This includes all steps of designing clinical and observational studies, analyzing and modelling clinical data and reporting, statistical learning and big data.
https://www.researchgate.net/profile/Catharina_Groothuis-Oudshoorn

Country

Netherlands

IAHPR Membership

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## Michał Kosma Jakubczyk, PhD

Michał Jakubczyk is an associate professor at the SGH Warsaw School of Economics, Poland. His research interests focus on decision theory, especially when applied to health, and on health technology assessment.

Country

Poland

IAHPR Membership

Tenured IAHPR Member Since 2018

## F. Reed Johnson, PhD

Dr. Johnson has more than 40 years of academic and research experience in health and environmental economics. He has served on the faculties of universities in the United States, Canada, and Sweden, as Distinguished Fellow at Research Triangle Institute, and currently as Professor in the Department of Population Health Sciences and Department of Medicine, Duke School of Medicine, as well as appointments in the Duke Clinical Research Institute, the Center for Health Measurement and the Duke Margolis Center for Health Policy. As a staff member in the US Environmental Protection Agency's environmental economics research program during the 1980s, Dr. Johnson helped pioneer development of nonmarket valuation techniques. These methods are now widely used in federally mandated regulatory impact studies, for estimating the value of improved health outcomes, and for quantifying patients' tolerance for treatment-related risks.

Dr. Johnson has nearly 150 publications in books and peer-reviewed journals. His research has been published in numerous medical, health-economics, environmental-economics, and general-economics journals. He led the first FDAsponsored study to quantify patients' willingness to accept benefit-risk tradeoffs for new health technologies. The study was used to inform FDA guidance on submitting patient-preference data to support regulatory reviews of medical devices. His current research involves quantifying patients' willingness to accept sideeffect risks in return for therapeutic benefits and estimating general time equivalences among health states.

In 2018 ISPOR awarded him the Donabedian Outcomes Research Lifetime Achievement Award. He is a founding member of the International Academy of Health Preference Research. He currently serves on the editorial board for The Patient, the External Environmental Economics Advisory Committee, and the ISPOR Health Science Policy Council.

Country

United States

IAHPR Membership

Founding IAHPR Member

## Emily Lancsar, PhD

Emily Lancsar is Head of the Department of Health Services Research and Policy at the ANU. Her broad research interests are in health economics, with particular interest in understanding and modelling choice, preferences and behaviour of key decision makers in the health sector.

Emily holds a number of current and past ARC, NHMRC, MRC, ESRC, NIHR and EU funded grants and fellowships. She is a member of a number of advisory committees including the Economic Sub-Committee of the Australian Medical Services Advisory Committee.

Prior to joining ANU in March 2018, Emily was an Associate Professor in the Centre for Health Economics at Monash University. Joining Monash in 2011 represented a return to Australia after spending more than 7 years at Newcastle University in the UK where she held Senior Lecturer and Lecturer positions in the Department of Economics. Emily also previously worked at CHERE in Sydney and at the Federal Department of Health. She is a past Vice President of the Australian Health Economics Society.

Country

Australia

IAHPR Membership

Founding IAHPR Member

## Deborah Marshall, PhD

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

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

## Richard Norman, PhD

Health Economist at Curtin University, Perth, Australia

Country

Australia

IAHPR Membership

Tenured IAHPR Member Since 2017

## Mark Oppe, PhD

Mark Oppe holds an MSc in astrophysics from Utrecht University and a PhD in health economics from Erasmus University Rotterdam. He has been working as a health economics researcher for 17 years and has more than 40 publications in various international peer reviewed journals.

He started as a health economics researcher at the Centre for Health Policy and Law of Erasmus University Rotterdam and as statistician for the Dutch renal registry Renine. From 2005 to 2012 he worked at the institute for Medical Technology Assessment (iMTA) at Erasmus University Rotterdam focusing on quantitative research related to economic evaluations in addition to teaching and various consultancy projects for industry.

From 2002 to 2018 Mark worked at the EuroQol Research Foundation where his work focused on methods for developing value sets for the EQ-5D. He was the lead developer of the EQ-VT, the standardised study protocol for obtaining EQ-5D-5L value sets and has supported valuation studies in more than 20 countries. From 2015 to 2018 he was the chair of the Descriptive Systems Working Group of the EuroQol Research Foundation, setting up and managing a multinational research programme.

Mark is a founding member of the International Academy of Health Preference Research (IAHPR) and external affiliate of the Erasmus Choice Modelling Centre (ECMC).

In January 2019, Mark joined Axentiva Solutions.

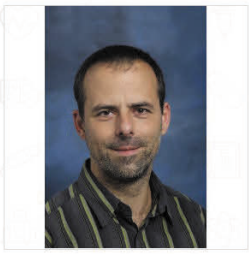
Country

Spain

IAHPR Membership

Founding IAHPR Member

## Jan Ostermann, PhD



Jan Ostermann, Ph.D., is Associate Professor in the Department of Health Services Policy & Management, Arnold School of Public Health, University of South Carolina in Columbia, and Adjunct Associate Professor at the Center for Health Policy & Inequalities Research, Duke Global Health Institute, Duke University in Durham, North Carolina. A key focus of Dr. Ostermann's work relates to characterizing individuals' preferences and decision making around health and preventive behaviors. Dr. Ostermann is currently PI on two studies that focus on preferences in the context of HIV: (1) an NIMH-funded R01 that evaluates the effect of a preference-informed HIV testing offer on testing uptake in a pragmatic randomized controlled trial; (2) a study that seeks to understand HIV risk and HIV prevention preferences of young adults who were orphaned or abandoned as children. He was previously PI for a Robert Wood Johnson Foundation grant to elicit the antiretroviral treatment preferences of HIV patients at two Infectious Diseases Clinics in the Southern United States and a national online panel. He was also PI, investigator and/or principal evaluator on other grants and contracts funded by NIH, UNICEF, and private foundations. Dr. Ostermann is interested in collaborating and pursuing funding opportunities around the further development and new applications of stated preference methods for valuation and decision-making in both resource-rich and resource-poor settings.

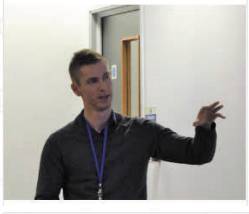
Country

United States

IAHPR Membership

Founding IAHPR Member

## Stephen Wesley Poteet, MA



Stephen Wesley Poteet, MA is currently completing his dissertation in the University of South Florida, Department of Economics under the direction of Phillip Porter, PhD and Benjamin M. Craig, PhD.

Country

United States

IAHPR Membership

Tenured IAHPR Member Since 2019

## Semra Ozdemir, PhD

Dr. Semra Ozdemir is an Assistant Professor at the Health Services and Systems Research Program and Lien Centre for Palliative Care at Duke-NUS Medical School in Singapore. She received her Ph.D. from the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. Dr. Ozdemir's main research area is medical decision making and health economics. Her research focuses on understanding preferences for treatments, health services and new health technologies, and developing interventions to help individuals make informed medical decisions. She has developed numerous discrete-choice experiment surveys to quantify patient and caregiver treatment preferences, and physician treatment recommendations in a variety of therapeutic areas, including cancer, chronic kidney disease, diabetes, chronic eye diseases, Crohn's disease, multiple sclerosis and bipolar disorder. Her research has been published in both economics and medical journals, including the Journal of Health Economics, Health Economics, Social Science and Medicine, Value in Health, Risk Analysis, Gastroenterology, and Medical Care.

Country

Singapore

IAHPR Membership

Tenured IAHPR Member Since 2016

## Jorien Veldwijk, PhD

Jorien Veldwijk holds a Masters' degree in Public Heath as well as in Clinical Epidemiology. Before starting her PhD she worked as a researcher at the Dutch National Institute for Public Health and the Environment. During that time she was involved in several research projects regarding the consequences of overweight among children, partly in collaboration with the World Health Organization. During her PhD she used Discrete Choice Experiments (DCEs) to determine individuals' preferences and their decision-making behavior regarding public health initiatives. She obtained her PhD in May 2015 and was appointed assistant professor at the University Medical Center Utrecht where her research continued to be focused on behavioral economics. Currently she continues working in the same research field using DCEs both at CRB and as a Senior Researcher at the Erasmus Medical Centre.

Country

Netherlands

IAHPR Membership

Tenured IAHPR Member Since 2017

## Shelby D Reed, PhD

Shelby Reed, PhD, RPh is Professor in Population Health Sciences and Medicine at Duke University and Director of the Center for Informing Health Decisions at the Duke Clinical Research Institute. Dr. Reed has 20 years of experience leading multidisciplinary studies in health economics and outcomes research. Dr. Reed has extensive expertise in designing and conducting trial-based and model-based cost-effectiveness analyses of diagnostics, drugs and patient-centered interventions. In her work on health policy issues, she developed computer models to evaluate the economic impact of trends in clinical trial design, changes in reimbursement policies, new financing schemes to spur drug development for ultra-rare conditions, and the societal value of alternative approaches to identifying drug safety problems. Her observation that stakeholders' adoption of research findings are dependent on their views of the relative importance of various outcomes led to her focus in stated-preference research.
In 2015, she co-founded the Preference Evaluation Research (PrefER) Group that focuses on applying stated-preference methods to evaluate benefit-risk tradeoffs, patient-centered value, and their application in comparative effectiveness research and clinical decision making. Dr. Reed earned pharmacy and doctoral degrees from the University of Maryland and completed her training in the Pharmaceutical Outcomes Research and Policy Program at the University of Washington. She serves on editorial advisory boards for Value in Health and Health Services Research. She is currently serving as Immediate Past-President of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR). She will be co-chair of the International Academy of Health Preference Research (IAHPR) in Chicago in October 2020.

Country

United States

IAHPR Membership

Founding IAHPR Member

## Janine Astrid van Til, PhD

Janine van Til is a health scientist by training. Janine started her work in preference research with her PhD project called "Integrating Preferences into decision making", which was focused on including values in decision making in the treatment of ankle-foot impairments in stroke patients. Janine is currently working as an assistant professor in the department of Health Technology and Services Management at the University of Twente in the Netherlands. Her research is focused on using preference methods, mainly discrete choice experiments, best-worst scaling and multi-criteria decision analysis to include the stakeholder perspective in health care decisions in the clinical, management and societal context. She has more than 10 years of experience in the design and analysis of stated preference surveys, mainly in the field of neurology, oncology and cardiology. Janine is the main supervisor of two PhD students in the field of patient preference research, and involved in the training of five other PhD students. Over the last five years she has successfully written multiple grant proposals, project managed national and international projects and worked as a consulting researcher in international projects. She is also the main lecturer of the course "Patient Preference Modelling" in the master Health Sciences at the University of Twente. In her non-research time, Janine likes to read books on the psychology of decision making and fantasy novels, imagines herself doing lots of sports and taking holidays, and is the proud mother of two very sassy boys.

Country

Netherlands

IAHPR Membership

Tenured IAHPR Member Since 2019

## Mo Zhou, PhD

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

# Regular Members in Attendance

## Blake Angell, BEc Soc Sci (hons), MPH, PhD

Blake is a Research Fellow (Health Economics) at the George Institute for Global Health, UNSW Sydney. He has experience working as a health economist in both academia and Government. His PhD was awarded in 2017 and examined the applicability and potential of common health economic methods in Indigenous populations in Australia and globally. His research since has focused on health systems issues predominantly in low and middle income nation contexts.

Country

Australia

## Bennett Levitan, MD-PhD

Bennett Levitan, MD-PhD is Senior Director, Benefit-risk Assessment, Department of Epidemiology at Janssen R&D, Pharmaceutical Companies of Johnson & Johnson. He introduced state of the art patient-focused benefit-risk assessment to Johnson & Johnson and his group has led numerous clinical teams in preparation of benefit-risk assessments and patient preference studies for regulatory submissions and health authority advisory meetings. He has co-led cross-disciplinary teams to implement processes to support growing regulatory requirements for patient-focused benefit-risk assessment both during development and post-approval. Bennett has published widely on both theoretical and pragmatic aspects in benefit-risk and patient preference studies and is a frequent speaker on these topics in national and international conferences. He co-led development of the PhRMA Benefit Risk Action Team (BRAT) Framework for drug benefit-risk assessment and the Medical Device Innovation Consortium (MDIC) Patient Centered Benefit-Risk Framework. Bennett serves on several committees that inform policy on benefit-risk methods including the IMI PREFER project on patient preference studies, the ISPE Benefit-Risk Assessment, Communication and Evaluation (BRACE) team, the CTTI Patient Groups & Clinical Trials work stream and the PhRMA Patient-Focused Drug Development Work Group. Bennett received his B.Sc. (Electrical Engineering) from Columbia University in New York and his M.D.-Ph.D. (Bioengineering) from the University of Pennsylvania and was a postdoctoral fellow at the Santa Fe Institute.

Country

United States

## Kim-Huong Nguyen, PhD

## Rachael DiSantostefano, PhD, MS

Rachael L. DiSantostefano, MS PhD, is a Senior Director of Benefit-Risk in the Epidemiology Department within Janssen Pharmaceuticals, R&D, LLC. She has 25 years of pharmaceutical research experience across the quantitative disciplines of epidemiology, biostatistics, and health outcomes. Over the course of her career as a methodologist, she has worked to design and deliver evidence across multiple therapy areas, including: Respiratory, Immunology, Neuroscience, Metabolic, and Oncology. Currently, she focuses on benefit-risk assessment and quantitative patient preference research. Dr. DiSantostefano is also an active member of PREFER, a 5-year public-private partnership that examines how and when to perform and include patient-preference studies in decision making during the medical product life cycle. Her research interests also include drug safety, retrospective observational studies, and innovation in observational studies.

Country

United States

## Michelle Owens, MA

My educational background is in psychology and my work experience predominantly has been in academia. Specifically, my passion lies in neuroscience research. Through work in clinical and non-clinical research studies, I have interviewed individuals experiencing a broad range of cognitive and emotional problems, including, Alzheimer's disease, attention-deficit/hyperactivity disorder, anxiety, and depression. As a compassionate person, I like to stay abreast of the latest treatments for these diagnoses, in hopes to provide information to others. Additionally, I have an understanding of the various mental health issues and social situations encountered by immigrants after a brief experience living abroad.

Country

United States

## Simon Pickard, PhD

UIC

Country

United States

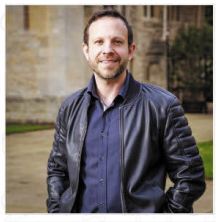
## Thomas G Poder, PhD

Investigator Thomas G. Poder holds a Ph.D. in economics and is specialized in cost-benefit analysis. He is interested in issues of effectiveness of new medical technologies and new ways of organizing care, as well as the efficiency of their use. He is also working to develop the measurement of quality of life of patients (QALY), to study the determinants of their health and to value the benefits of medical interventions.

Country

Canada

## Oliver Rivero-Arias, DPhil



Oliver Rivero-Arias is the Senior Health Economist at the National Perinatal Epidemiology Unit having previously held appointments at the Health Economics Research Centre (HERC), University of Oxford during the period 2002-2013. His main research interest concerns the evaluation of cost-effectiveness methodology and the conduct of applied economic studies in the perinatal and maternal health area. He has been involved in the evaluation of methods to handle missing data in cost-effectiveness analysis, the economic implications of cost-effectiveness analysis alongside multinational clinical trials, the development of algorithms to map available data into quality of life measures, and the elicitation of preferences for health decision-making. He has recently completed a study (currently under review) evaluating preferences of adolescents and adults to EQ-5D-Y health states using best-worst scaling and is currently a principal investigator of the valuation exercise to obtain a value set for the EQ-5D-Y in the UK funded by the EuroQol Research Foundation.

Country

United Kingdom

## Fern Terris-Prestholt, PhD

Fern's work focuses on the economics of new technology introduction for the prevention, diagnosis and treatment of HIV and related conditions (such as STIs), primarily in low and middle income countries.

Country

United Kingdom

## Vikas Soekhai, MSc, LLM

Vikas Soekhai has a background in health economics and health law. He worked as a research & development consultant at a major consulting company before starting his PhD. He will defend his thesis at the Erasmus University Rotterdam in late 2020. The PREFER project is a part of his PhD. He is supervised by Esther de Bekker-Grob (co-promotor and academic lead for the methodologies work stream), Bas Donkers (promotor and methodologies work stream member) and Ewout Steyerberg (promotor and methodologies work stream member). The promotors are from the Erasmus University Medical Centre Rotterdam and the Erasmus University Rotterdam and focus on choice modelling in healthcare.

Country

Netherlands

## Rosalie Viney, PhD

Rosalie Viney is Professor of Health Economics and Director of the Centre for Health Economics Research and Evaluation at the University of Technology Sydney. She has extensive experience in health economics, health services and health policy research. Her research interests include health technology assessment and priority setting, measurement and valuation of quality of life and health outcomes, consumer preferences for health and health care, evaluation of health policy, and the impact of funding arrangements on utilisation and outcomes of health care. Rosalie has undertaken a broad range of commissioned projects for State/Territory Health authorities, and for the Australian Government Department of Health. She is the program leader for the Cancer Australia funded national technical service providing health economics expertise and capacity building to national Cancer Clinical Trials Groups. Rosalie has also had longstanding involvement in the fields of health economics and health services research in Australia, through the Australian Health Economics Society and the Health Services Research Association of Australia and New Zealand. Rosalie is a member of the NHMRC Research Committee. Until March 2017 she was also a member of the Pharmaceutical Benefits Advisory Committee (PBAC) and Chair its Economics Sub-Committee.

Country

Australia

## Other Attendees

Paula Albuquerque, PharmD, MSc, MBA
Conny Berlin, Msc
Irina Cleemput, PhD
Nigel Scott Cook, PhD, Bsc (Hons)
Carlos Crespo Palomo, PhD
Gillian R Currie, PhD
Sheila Dickinson, MSc
Michael Frank Drummond, PhD
Alan Reid Ellis, PhD, MSW
Lidia Engel, PhD
Rocco Falchetto, PhD
Aureliano Paolo Finch, PhD
Mats Hanson, ThD
Sebastian Heidenreich, PhD
Hans Hillege, MD, PhD, MSc
Samare P.I. Huls, MSc
Christine Huttin, PhD MBA
Ruixuan Jiang, PharmD
Byron Jones, BSc, MSc, PhD
Suzana Karim, MA
Eva Katz, PhD, MPH, RD
Karen V MacDonald, MPH
Carol Anne Mansfield, PhD
Nikki McCaffrey, BSc(Hons) MSc PhD
Ann-Christin Mork, PhD
Ann-Christin Mork, PhD
Xinyi Ng, PhD
Bram Roudijk, Msc
Centaine Snoswell, PhD MPH BPharm
Trudy Sullivan, PhD
James Benjamin Tidwell, PhD
Laurenske Aleida Visser, MD, MSc
Chiara Whichello, MA MSc

## Future Meetings


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: "Giving a voice to marginalised groups for health care reform"
Abstract Deadline: Monday, September 18, 2019

### 12th Meeting of the International Academy of Health Preference Research

16-18 October 2020, Chicago, USA, chaired by **Ateesha Mohamed** and **Shelby Reed**
Workshops: "*Good research practices for health preference studies,*" **Derek Brown, Benjamin Craig**; "*Implementation of Individually Adaptive DCE Designs,*" **Marcel Jonker**
Symposium: "*No size fits all: preference elicitation to inform clinical decision making*"
Abstract Deadline: 3 August 2020

### 13th Meeting of the International Academy of Health Preference Research

2021, Europe/Africa, chaired by **Michał Jakubczyk** and **Jorien Veldwijk**

# Good Practices in Health Preference Research

Kirsten Howard, Emily Lancsar, Richard De Abreu Lourenço, Elisabeth Huynh
IAHPR Workshop, 8:00-12:00, 2 December 2019, Cliftons, Auckland, New Zealand

The 11th IAHPR Meeting will be held in Auckland, New Zealand and chaired by Richard De Abreu Lourenço and Elisabeth Huynh. Its first day will include a morning workshop on "Good practices in health preference research" and an afternoon symposium on "**Giving a voice to marginalised groups for health care reform.**"

The morning workshop will describe the basics on how to conduct a health preference study. Its hands-on exercise will cover examples of challenges faced during the assessment of preferences in marginalised groups, incorporating the experiences of the instructors. The workshop builds directly from the forthcoming textbook written by the IAHPR members.

**Learning objectives:**

- Introduces health preference research
- Introduces theoretical framework, and the basic types of studies
- Discusses components of a health preference study
- Covers research questions, the identification and description of attributes and levels, preference elicitation tasks, experimental design, survey instrument construction, and data collection as well as the analysis, interpretation, and presentation of the results.
- Describes the challenges of reviewing a HPR manuscript
- Illustrates the breadth of preference evidence and recent advances related to the symposium

**Course materials:**

Course booklet with slide deck (4 slides per page)
Hands-on exercise
Course evaluation

**Recommended materials:**

Methods for Health Preference Research, Oxford University Press (forthcoming)

**Outline:**

Introduction (~5 slides; 8:00-8:15), Kirsten Howard, Emily Lancsar, Richard De Abreu Lourenço, Elisabeth Huynh
- 1.1. Instructors (bios, disclaimers)
- 1.2. The Academy
- 1.3. Methods for Health Preference Research

Short Course Part I (~60 slides; 8:15-10:00), Kirsten Howard, Emily Lancsar
- 2.1. Introduction to health preference research and research question (~10 slides; Chapter 1)
- 2.2. Identification and description of attributes and levels (~10 slides; Chapter 2)
- 2.3. Preference Elicitation Tasks (~10 slides; Chapter 3)
- 2.4. Refinement of Choice Tasks (~10 slides; Chapter 4)
- 2.5. Experimental Design (~10 slides; Chapter 5)
- 2.6. Survey Instrument Construction (~10 slides; Chapter 6)

Break (10:00-10:15)

Short Course Part II (~35 slides; 10:00-11:00), Kirsten Howard, Emily Lancsar
- 2.7. Data Collection (~10 slides; Chapter 7)
- 2.8. Analysis (~10 slides; Chapter 8)
- 2.9. Interpretation and Presentation (~10 slides; Chapter 9)
- 2.10. Introduction to a summary checklist (~5 slides)

Hands-on Exercise (11:00-11:55), Richard De Abreu Lourenço, Elisabeth Huynh
- 3.1. Article break-out groups
- 3.2. Discussion
- 3.3. Symposium-related examples from the literature and review of the panel questions

Course Evaluation (11:55-12:00)

Faculty and Student Lunch (12:00-13:00)

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International Academy of Health Preference Research

# BUSINESS SESSION

Opening, Esther W. de Bekker-Grob, Meeting Co-Chair
Bylaws, Axel C. Mühlbacher, Vice Chair
Publications, Emily Lancsar, Director of Outreach
Meetings, Kirsten Howard, Director of Education
Sustainability, Benjamin Craig, Chair
Closing, Jennifer A. Whitty, Meeting Co-Chair

## OVERVIEW

IAHPR
International Academy of Health Preference Research

# OPENING

Esther W. de Bekker-Grob

Meeting Co-Chair

IAHPR
International Academy of Health Preference Research

# BYLAWS

Axel C. Mühlbacher

Vice Chair

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.

IAHPR
International Academy of Health Preference Research

**Foundation Board**

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

**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.

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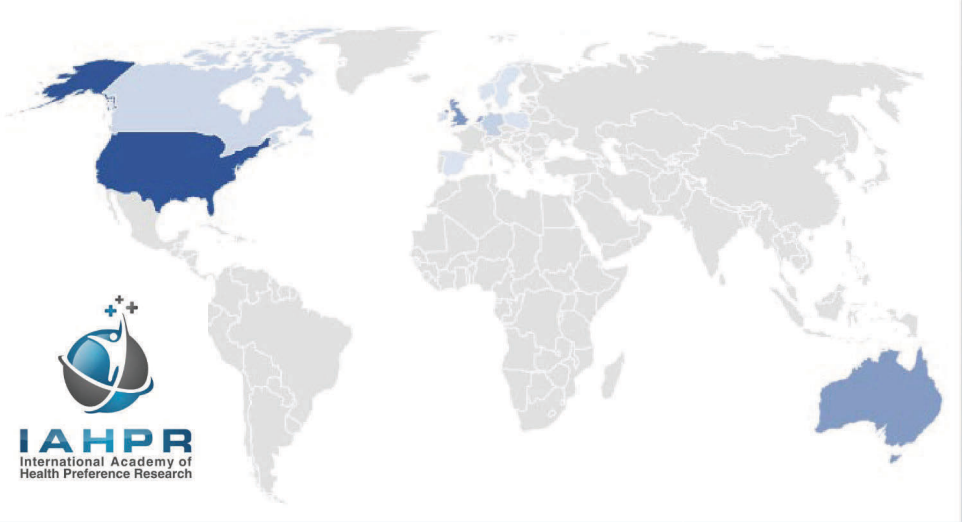
| | |
|---|---|
| USA | 29 |
| Australia | 19 |
| UK | 14 |
| The Netherlands | 10 |
| Germany | 4 |
| Canada | 4 |
| Ireland | 2 |
| Singapore | 2 |
| New Zealand | 2 |
| Norway | 1 |
| Poland | 1 |
| Spain | 1 |
| Sweden | 1 |




Our faculty (44 tenured and 46 regular members in 2019) 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 dues-only membership).

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

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REGIONAL DIRECTORS

6-YEAR TERM LIMIT

INCOMING CHAIR

# TRANSITION PLAN

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**ESTHER W. DE BEKKER-GROB**

**JENNIFER ANNE WHITTY**

# 2019 ELECTION

## REGIONAL DIRECTOR FOR EUROPE/AFRICA

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# 2020 REGIONAL DIRECTORS

*Europe/Africa (Election in 2019)*
Jennifer A. Whitty or Esther W. de Bekker-Grob (2020-2025)
Axel C. Mühlbacher (2015-2022)

*Asia/Pacific (Election in 2020)*
Emily Lancsar (2016-2020 or 2023)
Kirsten Howard (2017-2020 or 2023)

*North/South America (Election in 2021)*
Derek S. Brown (2014-2024)
Benjamin M. Craig (2014-2021)

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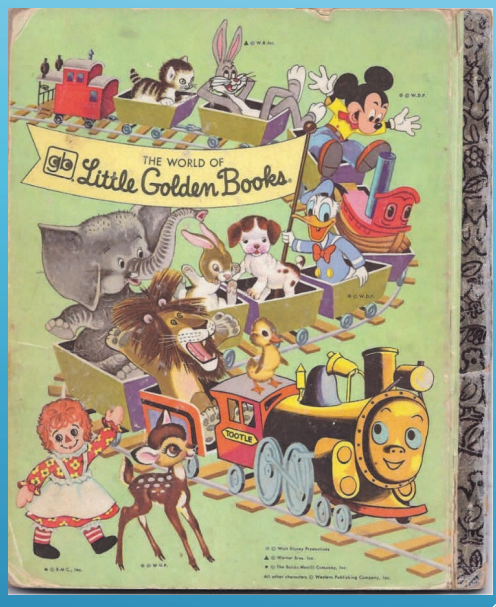
# PUBLICATIONS

Emily Lancsar

Director of Outreach

**STAGE-3 COMPILATION**

**Chapter 1** Introduction
**Chapter 2** Identification and description of attributes
**Chapter 3** Preference-elicitation task
**Chapter 4** Choice task construction
**Chapter 5** Experimental design
**Chapter 6** Survey instrument
**Chapter 7** Data collection
**Chapter 8** Analysis
**Chapter 9** Interpretation and presentation




# METHOD FOR HEALTH PREFERENCE RESEARCH

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**Stage 4** (Reviewing; mid-July to late August) has three objectives:
(1) **Solicit comments** on the chapters from targeted IAHPR members.
(2) Prepare revised and robust **outlines for the remaining content** of the book
(3) **Amend the chapters** as needed.

**Stage 5** (Harmonizing; September to late November) has two objectives:
(1) **Harmonize the first nine chapters** (i.e. D. Brown sabbatical)
(2) **Draft the remaining content**

**Stage 6** (Refinement; December to February) has two objectives:
(1) **Refine the first nine chapters**
(2) **Change requests for the remaining content**

# METHOD FOR HEALTH PREFERENCE RESEARCH

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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

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IAHPR
International Academy of Health Preference Research

2018, Vol. 12, No. 1 (pp. 1–XXX)
ISSN: 1178-1653 (Print); 1178-1661 (Online)

The Patient
Patient-Centered Outcomes Research
An Official Journal of the International Academy of Health Preference Research

# 10TH MEETING OF THE INTERNATIONAL ACADEMY OF HEALTH PREFERENCE RESEARCH

**Axel C. Mühlbacher**

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.

The 10th Meeting of the International Academy of Health Preference Research will be held on Saturday and Sunday, 13–14 July 2019 at the Volkshaus in Basel, Switzerland. Chaired by Esther W. de Bekker-Grob and Jennifer A. Whitty and hosted by Axel C. Mühlbacher, its activities include a workshop, a symposium, a networking dinner, and a scientific meeting.

On 13 July 2019, the Academy and Patient Preferences in Benefit and Risk Assessments during the Treatment Life Cycle (PREFER) will host a joint morning workshop on "Good research practices for health preference studies," led by Axel C. Mühlbacher. 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, incorporating the experiences of scientists working with PREFER.

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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]



The Patient - Patient-Centered Outcomes Research (2019) 12:281–285
https://doi.org/10.1007/s40271-018-0346-0

COMMENTARY

## Issues in the Design of Discrete Choice Experiments

Richard Norman[1] · Benjamin M. Craig[2] · Paul Hansen[3] · Marcel F. Jonker[4,5,6] · John Rose[7] · Deborah J. Street[8] · Brendan Mulhern[8]

The Patient – Patient-Centered Outcomes Research (2019) – Forthcoming Commentary

## Support Tools for Preference-Sensitive Decisions in Healthcare: Where Are We? Where Do We Go? How Do We Get There?

Jan Ostermann, Derek S. Brown, Janine A. van Til, Nick Bansback, France Légaré, Deborah A. Marshall, Meenakshi Bewtra

**Qualitative Reporting of Patient Experience (QRPE)**
**Steering Committee**

**Overview of Goals**

I am leading this collaboration to construct instructions for authors and reviewers interested in the reporting of qualitative evidence on patient experience for the primary purpose of designing quantitative studies on the patient perspective. Although qualitative research may be conducted to collect a broad array of patient-based evidence, this topical collection will focus on its use as a precursor to quantitative studies on the patient perspective. These instructions will be published in *The Patient* as the first article in a topical collection on Qualitative Evidence on Patient Experience. This initial article will have three main goals:

1) To provide instructions for authors who are conducting and reporting qualitative research and for reviewers who are evaluating those articles.
2) To clearly demarcate the necessity of qualitative research and the publication of their findings as a precursor to quantitative studies.
3) To set the stage for forthcoming changes in the field, such as meta-analyses of qualitative evidence, innovations in the reporting of qualitative evidence and the implementation of qualitative findings in subsequent study designs.

Ilene L. Hollin

# Qualitative Reporting of Patient Experience Initiative

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International Academy of Health Preference Research

# MEETINGS

Kirsten Howard

Director of Education

# SAVE THE DATE

## 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 |

Cliftons, Auckland, New Zealand
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: "*Giving a voice to marginalised groups for health care reform*"
Abstract Deadline: Monday, September 18, 2019

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Hobart, 2018

Starting in 2020:

1. **Annual,** instead of two per year
2. **Cycle** across 3 regions: North/South America, Europe/Africa, Asia/Pacific
3. **Extend the meeting length**, adding a half day.
4. **Organized and hosted by the regional directors**, not the IAHPR Office

Montréal, 2018

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University of Illinois Chicago Student Center West, Chicago, USA
chaired by **Ateesha Mohamed** and **Shelby Reed**
Workshops: "*Good research practices for health preference studies*" by **Derek Brown** and **Benjamin Craig**; "*Implementation of Individually Adaptive DCE Designs*" by **Marcel Jonker**
Symposium: "*No size fits all: preference elicitation to inform clinical decision making*"
Abstract Deadline: 3 August 2020

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

iahpr.org

IAHPR
International Academy of Health Preference Research

# SUSTAINABILITY

Benjamin M. Craig

Chair

Regular members:

1. No annual fees
2. Receive a $50 discount for each event
3. HPSTR subscription for free
4. The Patient subscription for free

Tenured members:

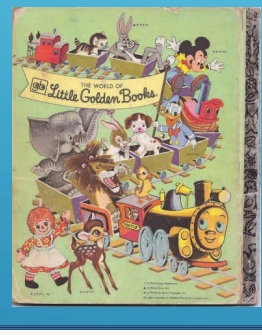
1. Pay for at least one event per year,
2. Attend all other events for free,
3. HPSTR contributors for free, and
4. Invited, but not required to vote, review abstracts, chair meetings, and lead other IAHPR activities.

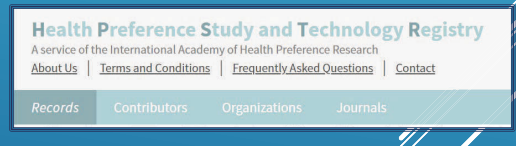
All memberships expire three years after the last meeting attendance.

Alternative service is available.

This reduces the Office duties to just the meeting registrations, abstract submission and review, website, HPSTR and the Patient.


Glasgow, 2017

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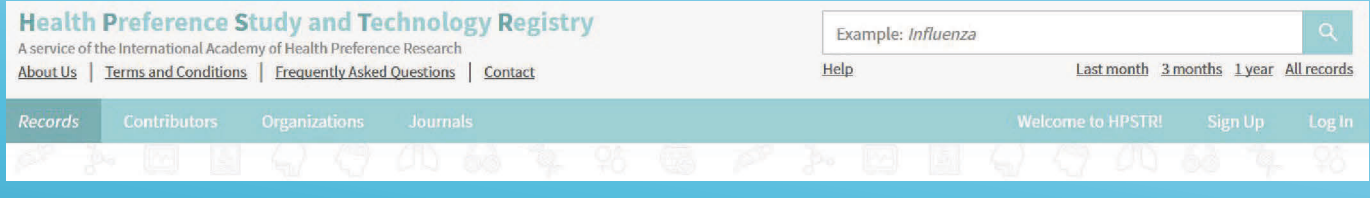
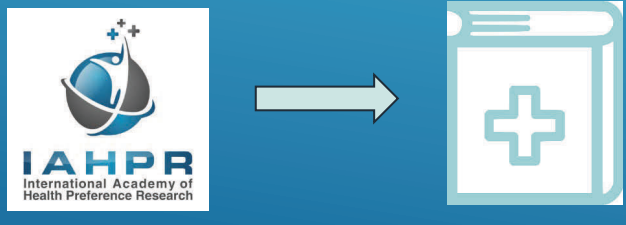



What is HPSTR.org?

HPSTR.org is a web-based resource that provides patients, their family members, health care professionals, researchers, and the general population with **easy access to information on publicly and privately supported health preference studies and technologies** on a wide range of diseases and conditions.

HPSTR.org is a collaborative initiative of the International Academy of Health Preference Research.



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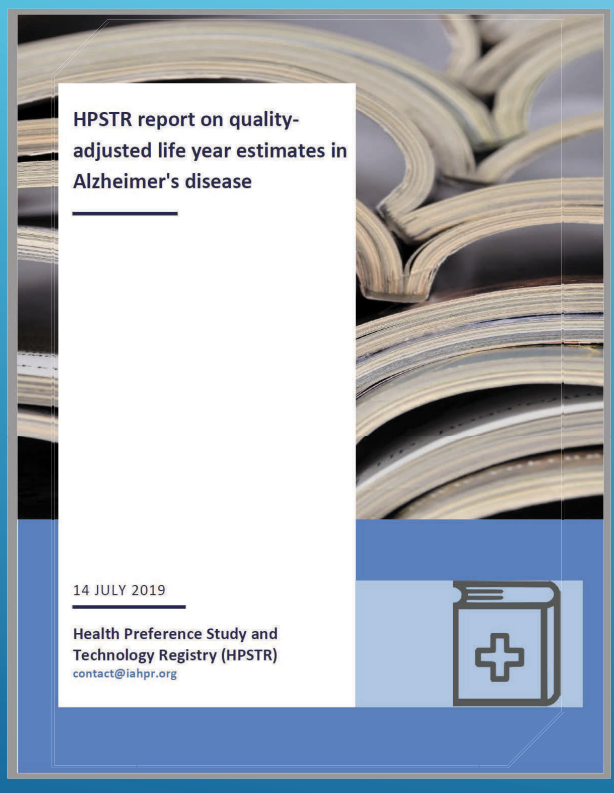


**HPSTR revenue goals:**

1. To collect enough revenue to sustain HPSTR
2. To make a profit to support IAHPR activities

**Activities to achieve these goals:**

1. Subscriptions
2. Submissions
3. Advertising
4. HPSTR Reports

**Nominations for topics?**

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# CLOSING

Jennifer A. Whitty

Meeting Co-Chair

Amsterdam, 2014

IAHPR
International Academy of Health Preference Research

Brisbane, 2015

Hamburg, 2016

St Louis, 2015

Singapore, 2016

Boston, 2017

Glasgow, 2017

Hobart, 2018

Montréal, 2018