

THE INTERNATIONAL ACADEMY OF HEALTH PREFERENCE RESEARCH  
IS PROUD TO ANNOUNCE

## THE 1<sup>ST</sup> MEETING OF THE INTERNATIONAL ACADEMY OF HEALTH PREFERENCE RESEARCH

SATURDAY, 8 NOVEMBER 2014  
8:00 TO 17:30

Chaired by Axel C. Mühlbacher, PhD, Hochschule Neubrandenburg



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Held in the Oseven Meeting & Congress Centre—located in the Passenger Terminal Amsterdam near Amsterdam Central Station—this 1-day meeting provides a forum to discuss innovative developments in the field of health preference research. The meeting includes over a dozen presentations, a business meeting, coffee break, lunch, and an offsite, post-meeting dinner.

POST-MEETING DINNER – 18:30 TO 22:00

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The post-meeting dinner is free for meeting attendees and includes a 6-course walking dinner menu and open bar. Tickets are available at the end of the meeting (no guests, please).

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# PROGRAM

**8:30-8:45 Welcome and Acknowledgement of Sponsors**

**Meeting Chair: Axel C. Mühlbacher**

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

A Methodological Exploration of Designing Discrete Choice Experiments with Duration to Model EQ-5D-5L Health States

**Brendan Mulhern**

Does the Choice of Health State Comparator or Ordering of Dimensions Matter when Valuing EQ-5D-5L?

**Koonal Kirit Shah<sup>ß</sup>**

Patient Preferences for Attributes of Disease Modifying Therapies: A Choice Based Conjoint Analysis

**Leslie Wilson<sup>ª</sup>**

Measuring Caregiver Treatment Preferences Using Best Worst Scaling and Conjoint Analysis

**John Bridges<sup>ª</sup>**

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

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

Response Time Data & Case 1 Best Worst Scaling Data: Separating “Gut” Attitudes from Those that Predict Preferences

**Terry Nicholas Flynn<sup>ª</sup>**

Using Eye-Tracking Methods to Inform Decision Making Processes in Discrete Choice Experiments

**Mandy Ryan<sup>ª</sup>**

Using Eye-Tracking to Explore the Framing of Risk Attributes in a Discrete Choice Experiment

**Caroline Mary Vass<sup>ß</sup>**

Survival or Mortality: Framing of the Risk Attribute in a Discrete Choice Experiment

**Jorien Veldwijk<sup>ß</sup>**

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

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

The Value of Diagnostic Information: Elicitation of the Money-Equivalent Value of Alzheimer’s Disease Tests?

**Axel C. Mühlbacher<sup>ª</sup>**

Incorporating DCE Uptake Prediction of New HIV Prevention Products into Cost Effectiveness Models

**Fern Terris-Prestholt**

From Choice-Experiment Data to Regulatory Intelligence: Constructing a Decision Tool

**F. Reed Johnson<sup>ª</sup>**

Incorporating Results from a Discrete Choice Experiment into a Discrete Event Simulation Model

**Rodolfo Andrés Hernández<sup>ß</sup>**

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

**14:45-15:30 Session 4**

Societal Willingness-to-Pay for Hemophilia Therapies in the US

**Shraddha S Chaugule<sup>ß</sup>**

Treatment Preferences of Patients with Metastatic Non-Small Cell Lung Cancer: A Discrete Choice Experiment

**Susanne Bethge<sup>ß</sup>**

**15:30-16:00 Open Discussion**

**16:00-17:00 Business Meeting**

**17:00-18:30 Break**

**18:30-22:00 Post-Meeting Dinner – Jamie Oliver's Fifteen (attendees only)**

<sup>ª</sup> indicates a member presenter

<sup>ß</sup> indicates a student presenter

# THE 1<sup>ST</sup> MEETING OF THE INTERNATIONAL ACADEMY OF HEALTH PREFERENCE RESEARCH

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8:45-10:15 Session 1

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### A Methodological Exploration of Designing Discrete Choice Experiments with Duration to Model EQ-5D-5L Health States

**Brendan Mulhern, MRes**, University of Sheffield, United Kingdom; **Nick Bansback, PhD**, University of British Columbia, Canada; **Arne Risa Hole, PhD**, University of Sheffield, United Kingdom; **Aki Tsuchiya, PhD**, University of Sheffield, United Kingdom

**Background:** Recently, it has been shown that discrete choice experiments incorporating an attribute for duration (known as DCETTO) can be used to derive health state values for descriptive systems such as the EQ-5D-5L that are anchored on the full health - dead utility scale. However, methodological issues remain relating to: the levels and values used for the duration attribute; and the optimal way to select the health state pairs.

**Purpose:** The purpose of this study is threefold: 1. to investigate the impact of increasing the number of duration levels used and the number of pairs in the model where duration varies; 2. to compare models derived from two different designs – one with zero priors (Type Ia design) and one with non-zero priors (Type Ib design); 3. to investigate a method of allocating duration to EQ-5D-5L health state pairs designed without a duration attribute (Type II design)

**Methods:** To investigate aims 1 and 2, two sets of study designs each including 120 pairs of health profiles made up from EQ-5D-5L health states combined with one of six duration levels were selected using a D-optimality algorithm with zero and non-zero prior values for the health state dimension level coefficients. This was done using the DCE design software NGene. For aim 3, 120 EQ-5D-5L health state pairs were selected using stata, and duration levels were allocated to the pairs based on the estimated utility value of the health state taken from an earlier study by the authors (the PRET-AS study; Bansback et al., 2014) where we aimed to achieve a 60-40 to 70-30 proportion split between the choices. An online sample of 2,002 members of the UK general population (802 Type Ia; 800 Type Ib; 400 Type II) representative in terms of age and gender completed 10 DCETTO tasks each. Data were analysed using conditional logit modelling and the impact on the predicted values derived were compared to the earlier PRET-AS work. Differences across the models derived from the designs with zero and non-zero priors were assessed.

**Results:** The Type Ia design (with zero priors) produced a model with coefficients that are generally logically ordered. The Type Ib design (with non-zero priors) resulted in a set of less ordered coefficients, and the models significantly differ to each other. The Type II design resulted in a generally logically ordered and significant model.

**Conclusions:** There is some indication of compromised “respondent efficiency,” suggesting that the use of non-zero priors (taken from the results of a similar DCETTO study) will not necessarily result in better overall outcomes. Allocating duration values to EQ-5D-5L health state pairs based on their estimated utility value is feasible.

### Does the Choice of Health State Comparator or Ordering of Dimensions Matter when Valuing EQ-5D-5L?

**Koonal Kirit Shah, MSc**, and **Brendan Mulhern, MRes**, University of Sheffield, United Kingdom

**Background:** Studies to produce utility values for the EQ-5D-5L instrument are ongoing internationally. These include the valuation of EQ-5D-5L health states using the time trade-off (TTO) and discrete choice experiment (DCE) methods. In some of the studies carried out to date, relatively low mean TTO values for mild health states have been observed. It is hypothesised that this is because the health states under evaluation are being compared to “full health”, whereas in previous studies they were compared to 11111 (the “best” health state in the descriptive system). Another key feature of the tasks is the order in which the health state dimensions are presented to respondents. Respondents may use a variety of heuristics



when completing valuation tasks (for example focusing on the first dimension presented). It is hypothesised that the relative importance that respondents place on different dimensions is affected by the order in which the dimensions are presented to them.

**Purpose:** To assess the impact on health state valuations of using two different comparators (full health and 11111) and three different dimension orderings.

**Methods:** Preferences for EQ-5D-5L health states were elicited from a broadly representative sample of members of the UK general public. TTO and DCE data were collected using computer-assisted personal interviews, carried out in respondents' homes. Respondents were randomly allocated to one of six arms that determined the TTO comparator health state (full health or 11111) and the dimension ordering in both the TTO and DCE tasks. After completing the valuation tasks, the respondents were asked follow-up questions which sought to examine their interpretations of the term "full health". Differences in mean values and the relative importance of the coefficients across the arms were assessed using difference testing and regression analyses.

**Results:** 450 interviews were completed in mid-2014. Health state 11111 was almost always given a value of 1; yet the majority of respondents who self-reported as being in 11111 did not consider themselves to be in "best imaginable health". Preliminary analyses suggest that the use of 11111 (rather than full health) as the comparator does not increase the average values elicited for mild health states. A sizeable minority of respondents did not agree that 11111 and full health are equivalent. Vision and spirituality were mentioned by respondents as examples of important aspects of health not covered by 11111. Descriptive analysis suggests that there are minimal differences between the mean TTO health state values across the different dimension orderings. Regression analysis suggests that the magnitude of the dimension coefficients differs across the different dimension orders (for both TTO and DCE), but there is no clear pattern.

**Conclusions:** The low observed values for mild EQ-5D-5L health states cannot be explained by the choice of comparator health state alone. There is some evidence that the order in which the dimensions are presented affects the coefficients, which may affect the health state values generated.

### **Patient Preferences for Attributes of Disease Modifying Therapies: A Choice Based Conjoint Analysis**

**Leslie Wilson, PhD**, University of California—San Francisco, United States; **Christine Bui, PharmD**, University of California—Davis, United States

**Purpose:** Disease modifying therapies (DMTs) decrease relapses in patients with multiple sclerosis (MS). Due to their wide variety of risk/ benefit attributes, patients must weigh their preferences when choosing DMTs. We determine patient preferences for DMT's risk/benefit attributes.

**Methods:** Our choice-based conjoint (CBC) survey developed using Sawtooth software was given in-person, to 300 consenting adults with relapsing remitting MS at University of California, San Francisco's MS clinic. Each patient answered 16 choice tasks. They chose one of two choices with 3-4 different levels of 6 risk and benefit attributes of hypothetical DMTs. Benefits included delayed progression, reduced relapses, and symptom improvement. Risks were mild side effects (SEs), serious SEs, and administration route and frequency. Analysis used mixed-effects logistic regression.

**Results:** Patients were 76% female; 75% with mild, 18% moderate, and 7% severe disease. All 6 attributes significantly impacted patient preference. Of the benefits, the preferences were highest for preventing progression 10 vs 2 years (odds ratio [OR]=2.27,  $p<0.001$ ) and for substantial vs no improvement in symptoms (OR=3.67,  $p<0.001$ ). Patients may be willing to accept a 0.05-0.1% risk of serious SEs leading to death (OR=0.57-0.66;  $p<0.001$ ) to gain a moderate to substantial benefit from their therapy. A 1% risk of serious SE compared to no risk (OR=0.22,  $p<0.001$ ) resulted in very low preference, but had a comparable magnitude in preference to a substantial improvement in symptoms vs no improvement (OR=1.60,  $p<0.001$ ). Compared to daily subcutaneous administration, patients preferred daily oral administration (OR=2.15,  $p<0.001$ ), then monthly intravenous (OR=1.54,  $p<0.001$ ), and then intramuscular weekly (OR=1.19,  $p<0.01$ ).

**Conclusions:** Patients are willing to make risk/benefit tradeoffs in medication selection. Their strongest benefit preference is for treatments that improve their symptoms substantially (not a proven DMT benefit)

and the least for relapse prevention (the primary outcome of many DMT clinical trials). Oral and monthly administration is preferred.

### Measuring Caregiver Treatment Preferences Using Best Worst Scaling and Conjoint Analysis

**Ilene Hollin, MPH; Holly Peay, MS; and John Bridges, PhD, Johns Hopkins University, United States**

**Purpose:** Under its patient-centered drug development program, the FDA aims to better understand the perspectives of patients and caregivers for 20 diseases. Parent Project Muscular Dystrophy (PPMD) developed, implemented, and disseminated a community-centered approach to study patient and caregiver preferences for Duchenne Muscular Dystrophy (DMD). DMD is a rare, progressive disease with no FDA approved medicines. Though not one of FDA's chosen 20 diseases, PPMD began a research program on DMD treatment preferences. In this study lead by PPMD, we aimed to compare two stated-preference methods: best worst scaling (BWS) case 2 (profile case) and conjoint analysis using a take-it-or-leave-it choice formats. These two approaches were used within a single study focused on measuring caregivers' preferences for the benefits and risks of emerging treatments for DMD.

**Methods:** Both the BWS and conjoint analysis elicitation format were used on a single underlying experiment. Using a main-effects orthogonal array, 18 potential treatments were developed using six attributes (each defined across three levels) that were previously identified using a rigorous community-engaged approach. For each treatment profile, respondents were asked to identify what they viewed as the best and worst feature. They were also asked "If the treatment were real, would you use it for your child?" Good research practices were used in analyzing the data, and unadjusted results were compared graphically.

**Results:** The caregiver survey respondents (n=119) were more often married (90%), Caucasian (92%), biological mothers (67%). We identified a statistical and qualitative difference between the two approaches, even when accounting for differences in scale across the results of the two experiments. While benefits and risks were similarly evaluated, differences across the two methods were identified for both nausea and post-market data knowledge about the drug. For both of these attribute, monotonicity (i.e. an upward slope) was observed for BWS, but for both attributes discontinuities in slope were identified using conjoint analysis.

**Conclusions:** BWS and conjoint analysis produced similar results for benefits and risks, but not for the other attributes. The lack of monotonicity for nausea and post-market data in the conjoint analysis could not be explained by stratifying by disease severity or via latent class analysis, leading us to assume that it was due to some unobserved framing effect within the conjoint-analysis elicitation format. More research is needed to study differences between stated-preference methods.

## 10:30-12:00 Session 2

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### Response Time Data & Case 1 Best Worst Scaling Data: Separating "Gut" Attitudes from Those that Predict Preferences

**Terry Nicholas Flynn, BA, MSc, PhD, Australia; Elisabeth Huynh, BComm, PhD, University of South Australia, Australia; Charlie Corke, MBBS, Geelong Hospital, Australia; Guy Hawkins, PSych, PhD, University of New South Wales, Australia**

**Purpose:** To understand whether supplementing Case 1 (Object Case) best-worst scaling (BWS) data to quantify attitudes towards end-of-life care with response time data produced similar results or whether attitudes like 'A Methodological Exploration all life is sacred' merely evoke 'fast, gut' responses of the Kahneman type which do not predict preferences.

**Methods:** 1186 respondents aged 55+ in Australia answered two online discrete choice experiments, which logged how long they took per mouse click. One DCE was a simple "accept/reject treatment" response to a full factorial in 16 (4x2x2) hypothetical realistic end-of-life clinical scenarios. The other was a Case 1 BWS

study in 13 choice sets to quantify degree of agreement with 13 attitudes towards end-of-life care spanning various concepts including “pro-life”, “pro-quality of life” and “control over decision-making”. A Balanced Incomplete Block Design was used to ensure equal occurrences and co-occurrences and minimise respondent tendency to infer the researchers’ intentions. Respondents who obviously did not do the tasks in a reasonable timeframe were deleted. Traditional logit-based BWS models of the choice data were compared with hierarchical Bayesian implementation of the best-worst Linear Ballistic Accumulator (LBA) models published in 2013 and 2014 which conceptualise the random utility model as a “horse race” type psychological process.

**Results:** Certain divergencies arose from the two models. Most notably (1) the 'considered response' (I would prefer a course of treatment that focused on extending life as much as possible, even if that meant more pain and discomfort) and the 'gut response' (all human life is sacred) are approximately equally disliked in the choice data. However, (2) when adding the response times the 'gut response' is disliked far more. Three DCE segments were found, (1) the largest, close to two thirds, virtually always rejected treatment, (2) the second, close to one third, switched answers depending on the attribute levels on offer, (3) the smallest (7-9%) virtually always wanted treatment.

**Conclusions:** DCEs to elicit advance care plans involving complex clinical scenarios are difficult. Case 1 BWS studies that successfully predict preferences from more general attitudes would help uptake of advances care planning. Since the DCE showed that the vast majority of Australians wanted care to improve symptom management and quality of life, rather than life extension, attitudes that help distinguish those one third of Australians with 'it depends' preferences are far more helpful in advance care planning than ones that simply induce strong disagreement - with little to no predictive ability of preferences - rather than consideration. This study provides strong quantitative evidence supporting a priori hypotheses the authors had concerning which attitudes are likely to be helpful in predicting preferences.

### Using Eye-Tracking Methods to Inform Decision Making Processes in Discrete Choice Experiments

**Mandy Ryan, PhD; Nicolas Krucien, PhD; and Frouke Hermens, PhD, University of Aberdeen, Scotland**

**Context:** The increased use of discrete choice experiments (DCEs) in health economics has been accompanied by an interest in how individuals respond to such choice tasks. More specifically, researchers have questioned whether individuals respond to DCEs in the way economic theory predicts. Quantitative methods employed have been argued to be limited in addressing this question. In this paper we explore the use of eye-tracking methods to shed further light on how individuals respond to DCEs, focusing on insights from analysis of data on visual attention to attributes.

**Purpose:** To better understand how individuals respond to DCEs and to improve the modelling of preferences by recording the visual attention of participants to a DCE.

**Methods:** An existing DCE designed to elicit preferences for diet and exercise programmes was used. Twenty-eight students completed 11 choice tasks whilst an eye-tracking system recorded their visual fixations. Analysis looked initially at visual fixations across alternatives and attributes. Five models, reflecting different assumptions about visual attention and choices, were then estimated and compared to the ‘standard’ DCE model. Goodness of fit (AIC) and willingness to pay were compared across models.

**Results:** Visual fixation data indicated a left to right bias, top to bottom bias and evidence of attribute non-attendance (ANA). Modelling visual attention impacted on parameter estimates. The best fitting model was where visual attention and attributes values were modelled as two separate sources of influence on the respondents’ choices. There was also evidence that increased visual attention reduced the model’s variance.

**Conclusion:** Visual attention data provided useful insight into DCE response data. Evidence of a left-to-right and top-to-bottom bias suggests practitioners should randomise order of alternatives and attributes. Evidence was presented of zero fixation time for some attributes, indicating ANA. Incorporating visual attention into DCE models improved model fit, potentially improving the validity of welfare estimates and thus the delivery of healthcare. Future areas for research are suggested.

### Using Eye-Tracking to Explore the Framing of Risk Attributes in a Discrete Choice Experiment

**Caroline Mary Vass, MSc; Dan Rigby, PhD; Stephen Campbell, PhD; Kelly Tate, BSc; Andrew Stewart, PhD; and Katherine Payne, PhD, University of Manchester, United Kingdom**

**Purpose:** To understand how the communication of risk in a discrete choice experiment (DCE) affects respondents' decision making heuristics and strategies.

**Method:** A pilot DCE was designed to understand the preferences of female members of the public (recruited by posters in local cafes) for a breast screening programme described by three attributes (probability of detecting a cancer, risk of unnecessary treatment, and out-of-pocket cost) each with four levels. Two survey styles were used that varied how the risk attributes (probability of detecting a cancer and risk of unnecessary treatment) were presented as: (1) a percentage or (2) a percentage and icon array. Two approaches were used to understand how, and if, these risk communication methods affected respondents' decision making strategies: eye-tracking and retrospective think aloud cognitive interviews. Eye-movements were recorded as a series of co-ordinates 1,000 times a second. Eye-tracking data were analysed in terms of direction of motion and total visual attention (dwell time) to pre-defined areas of interest using descriptive statistics. Immediately after completing the last choice question, respondents were asked a series of debriefing questions. The effect of each attribute on the women's preferences were analysed using a conditional logit model.

**Result:** Twenty female members of the public completed the DCE and fifteen completed the DCE in the eye-tracking experiment. Respondents gave significantly more visual attention, indicating information processing, to both risk attributes when risk was communicated with an icon array rather than solely as a percentage with a mean dwell time of 6316 and 5043 milliseconds, respectively. Respondents to the icon array version also exhibited significantly more upwards and downwards eye-movements (43% v 38% of saccades) suggesting calculations were made in line with expected utility theory possibly reflecting a greater understanding of the risk information. The eye-tracking data confirmed the self-reported attribute non-attendance as stated by respondents when asked the de-briefing questions with significantly lower (by almost 70%) mean dwell times to these attributes. The results of the conditional logit revealed both probability of detecting a cancer and the risk of unnecessary treatment were significant in women's decision to partake in breast screening.

**Conclusion:** This pilot study demonstrates that eye-tracking can be used as a method to further understand DCE responses. The pilot study also highlights the impact attribute framing can have on respondents' decision making strategies and choices.

### Survival or Mortality: Framing of the Risk Attribute in a Discrete Choice Experiment

**Jorien Veldwijk, MSc, National Institute for Public Health and the Environment, The Netherlands; Brigitte Essers, PhD, Maastricht UMC, The Netherlands; Carmen Dirksen, PhD, Maastricht UMC, The Netherlands; Henriette Smit, PhD, UMC Utrecht, The Netherlands; Mattijs Lambooij, PhD, National Institute for Public Health and the Environment, The Netherlands; G. Ardine de Wit, PhD, National Institute for Public Health and the Environment, The Netherlands**

**Purpose:** To empirically test whether and how framing of a risk attribute in a Discrete Choice Experiment (DCE) affects study results with respect to relative importance of the attributes, trading behavior and potential uptake rates.

**Methods:** By means of ongoing data collection, two versions of a DCE- questionnaire containing nine D-efficiently designed choice tasks were distributed among a representative sample of the Dutch population aged 55-65years. The DCE consisted of four attributes related to the decision whether to participate in genetic screening for colorectal cancer (CRC). Three fixed attributes were; risk of being genetically predisposed, risk of developing CRC, and frequency of follow-up colonoscopies. The included risk attribute was framed positively as survival rate and negatively as mortality rate. Mixed logit models were conducted to estimate the relative importance of the attributes. Dominant decision behavior was determined and potential uptake rates were calculated.

**Results:** Overall, risk attribute framing significantly interacted with most of the attribute level estimates.



Based on the positive frame, the frequency of follow-up colonoscopies was most important followed by survival rate, while based on the negative frame, mortality rate was most important. Twice as many respondents dominated on the survival attribute compared to the mortality attribute. Potential uptake rates were calculated for multiple hypothetical scenarios, in all cases they were lower based on the data of the negative frame.

**Conclusion:** The use of a positive frame leads to significantly increased frequency of dominant choices. Negative framing of the risk attribute resulted in a different relative importance of the attributes and a lower willingness to participate in genetic screening for CRC compared to positive framing. These results call for greater attention and more research with regard to the impact of framing of risk attributes in DCEs aiming to elicit preferences within the health care or public health context.

## 13:00-14:30 Session 3

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### The Value of Diagnostic Information: Elicitation of the Money-Equivalent Value of Alzheimer's Disease Tests?

**Axel C. Mühlbacher, PhD, MBA,** Hochschule Neubrandenburg, Germany; **F. Reed Johnson, PhD,** Duke University, United States; **Jui-Chen Yang, MEM,** Triangle Health Preference Research, United States

**Purpose:** Lack of diagnostic certainty or possible distress related to positive results could limit application of new testing technologies. However, diagnostic information could inform contingency planning or have the intrinsic value of “just knowing.” Quantifying patients’ perceived value of diagnostic information can inform development of testing guidelines and decisions about investments in testing technologies. The aim of the empirical study was the quantification of preferences of the general public for Alzheimer’s Disease test technologies and the perceived value of diagnostic information, applying discrete-choice experiment (DCE) and contingent-valuation (CV) questions

**Method:** The survey presented respondents with a series of DCE questions. A fractional factorial experimental design with 36 choice questions was constructed using a D-optimal algorithm. Each profile was defined by three attributes Diagnostic test cost was included as an attribute in the choice questions to estimate the money-equivalent value (MEV), for improvements in the levels of the diagnostic test attributes. In addition to the discrete-choice question format, CV questions were included to capture the value of diagnostic test information assuming treatment is available to patients. The preference data were analyzed using random-parameters logit models. In particular, relative importance is indicated by the MEV of utility differences. For the specified linear-additive indirect utility function, MEV for test characteristics is the expected mean compensating-surplus welfare measure for respondents with an interest in the specific test attribute. Ex ante MEV accounts for the probability of being “in the market” for a particular test and thus is the value of having the test in the individual’s choice set. These estimates were calculated using the standard random-utility log-sum formula

**Results:** A total of 1615 respondents (800 in UK, 815 in Germany) completed the survey. 281 respondents chose the no-test alternative in all the DCE questions and did not express an interest in the diagnostic test described in the CV question even at zero cost. Although mean parameters were similar, all standard-deviation measures of taste heterogeneity for Germany were significantly larger than UK estimates. There were no statistically significant differences between country samples in mean preference-parameter estimates for either test characteristics or cost. The preference weights were then used to calculate ex ante mean MEV for AD test profiles. The most valued diagnostic test was brain imaging without radioactive markers with best test precision, with estimated MEVs of €342 among German respondents and €704 among UK respondents. The least valued diagnostic test was spinal tap with worst test precision, with estimated MEVs of €49 and €37 among German and UK respondents, respectively.

**Conclusion:** This study focused on the value of AD diagnostic test information for respondents who were asked to evaluate tradeoffs among test characteristics and cost. Analysis yielded preference estimates indicating the relative importance of diagnostic test characteristics, as well as monetary value estimates.

The CV questions showed that a surprisingly large percentage of respondents were not willing to take a diagnostic test or did not state any interest. The likelihood of rejecting diagnostic information was correlated with various attitude and health-history variables.

### **Incorporating DCE Uptake Prediction of New HIV Prevention Products into Cost Effectiveness Models**

**Fern Terris-Prestholt, PhD**, London School of Hygiene and Tropical Medicine, United Kingdom; **Matthew Quaife, BA**, London School of Hygiene and Tropical Medicine, United Kingdom; **Peter Vickerman, PhD**, University of Bristol, United Kingdom

**Purpose:** Mathematical modelling studies have shown the importance of more efficacious products, and user uptake and adherence on the impact of new prevention technologies (NPTs). However, to date these models have relied on uptake assumptions based on expert opinion or existing technologies, rather than empirical data such as discrete choice experiments (DCEs). A recent DCE study explored South African women's preferences for women initiated HIV prevention products and found a large impact of product effectiveness and higher uptake among those who did not use condoms. To improve mathematical models estimating the impact of the introduction of new HIV technologies, we compare the conventional approach of modelling product uptake as independent from product effectiveness with a new approach that accounts for estimates of product uptake by product effectiveness obtained from DCE data.

**Methods:** DCE data are used from a study among 1017 South African women in Greater Johannesburg, South Africa. This DCE elicited preferences for the characteristics of new women initiated HIV prevention technologies (Female condom, male condom, the diaphragm, microbicides and 'use no HIV prevention'). This study uses empirically estimated predictions of uptake to model the average population protection provided when introducing microbicides, accounting for the differential uptake by product effectiveness and use of condom and compares this to assumptions of 30% uniform uptake among non-condom users only.

**Results:** Combined population protection, where condom use is 20% and the microbicide is moderately (55%) effective, is predicted at 30%, of which 17% attributable to condoms and 13% to new microbicide uptake. The DCE data suggests uptake of a 55% effective microbicide would only be 16% among non-condom users and lead to 2% condom substitution, predicting only 23% combined protection. At 60% condom use, uniform uptake predicts 58% protection, which differential uptake predicts 53% protection. However, at high product effectiveness (95%), population protection using user preferences is predicted at 68%, above the uniform uptake predictions of 62%.

**Conclusions:** This study shows microbicide impact using uniform uptake predictions are likely to be overestimated for moderately effective products while underestimated for highly effective products. Not accounting for this differential effect is likely to lead to biased models and inefficient allocation of resources. As such quantitative data on drivers of uptake rare for new prevention technologies, this study proposes the use of hypothetical DCE data to strengthen our impact models.

### **From Choice-Experiment Data to Regulatory Intelligence: Constructing a Decision Tool**

**F. Reed Johnson, PhD**, Duke University, United States

**Purpose:** The U.S. Food and Drug Administration (FDA) sponsored the first discrete-choice experiment (DCE) study to provide regulatory-quality evidence on patients' willingness to accept benefit-risk tradeoffs. The study quantified obese individuals' willingness to accept inconvenience, side-effect risks, and mortality risks in return for weight loss and weight-loss duration. Conventional reporting practices for DCE benefit-risk studies include basic information about survey development, data collection, and analysis. However, regulatory users of such studies needed to know minimum acceptable benefits for given benefits and maximum acceptable risks for given benefits for novel weight-loss devices with specific features, precision levels of risk-tolerance values, and the distribution of risk tolerance for the specified device in the target population.

**Methods:** The choice model was estimated using random-parameters logit with effects-coded categorical

variables and Box-Cox transformed nonlinear continuous variables. Unobserved preference heterogeneity was assumed to be normally distributed. Trade-off preferences were elicited in an ex-ante framework over probabilities. Evidence on benefits and risks are in the form of ex post, realized outcomes observed in clinical trials. Simple extrapolations of parameter estimates initially resulted in implausible results, including incorrect signs, for values derived from the tails of distributions and extreme values of explanatory variables. These problems were resolved by (1) accounting for differences between realized and expected utility allowing for likelihood of being in the market to calculate risk tolerance (see Figure 1) and (2) censoring simulated empirical distributions to prohibit extrapolations beyond the range of the data. The interface was revised in a series of interactions with FDA staff and regulatory reviewers to improve clarity and usability of the tool.

**Results:** Users enter device characteristics, including weight loss or mortality risk, duration of weight loss, dietary restrictions, severity, and duration of side effects, co-morbidity benefits, and type of surgery. If weight-loss is specified, the tool calculates minimum acceptable risk with confidence intervals and quartiles of the preference distribution. If risk is specified, the tool calculates minimum acceptable weight loss along with precision and distribution information. The display also shows the relative contribution of each attribute level to the overall acceptable risk or acceptable benefit value. The decision tool has been tested in FDA evaluations of new weight-loss device submissions. Reviewers report that the tool is easy to use and provides important information on patient values previously lacking in regulatory deliberations. FDA currently is drafting guidance for including the required patient-preference data in approval applications to implement similar decision tools for other new health technologies.

**Conclusions:** Stated-preference researchers often target the results of their studies at other researchers. Translating preference findings into forms relevant to support decision making requires re-examination of model assumptions and calculations not usually reported in documenting such studies.

### **Incorporating Results from a Discrete Choice Experiment into a Discrete Event Simulation Model**

**Rodolfo Andrés Hernandez, MSc**, University of Aberdeen, United Kingdom; **Luke David Vale**, University of Newcastle, United Kingdom; **Mandy Ryan, PhD**, University of Aberdeen, Scotland; **Jennifer Margaret Burr**, University of St Andrews, United Kingdom

**Background / Motivation:** Health Technology Assessment (HTA) focuses on Quality Adjusted Life Years (QALYs) as the main valuation method but this approach does not capture factors beyond health important to patients and the public. Discrete choice experiments (DCE) have been extensively used to value such factors. However, examples of the use of DCEs within an economic evaluation framework are limited. In this paper we incorporate the output of a DCE into an economic evaluation based upon a Discrete Event Simulation (DES). The case study is monitoring individuals with ocular hypertension at risk of developing open angle glaucoma (OAG). We compare policy recommendations from cost-benefit analysis (CBA), using willingness to pay (WTP) values generated from a DCE, and cost-utility analysis (CUA) using EQ-5D generated QALYs.

**Methods:** An advisory panel and patient focus group identified seven attributes with associated levels for the **DCE**: risk of developing glaucoma, severe glaucoma and visual impairment; unwanted effects of treatment; communication and understanding; monitoring location and a price proxy. A pilot study (n=183) elicited prior information to inform the main survey's D-efficient design. Images were used to explain glaucoma disease stages and risk levels. Data were collected using an internet panel survey and analysed using a multinomial logit. WTP estimates were generated and incorporated into a DES model. EQ5D data were obtained from 255 people with glaucoma sampled from eye care services and a glaucoma patient-based organisation. EQ5D estimates for ocular hypertension were assumed equal to mild glaucoma. Five monitoring strategies were compared - four 'active monitoring' and one 'treat-all'. For the active monitoring two strategies were based on National Institute for Health and Care Excellence (NICE) guidelines with monitoring interval and treatment depending on initial risk stratification: 'NICE intensive' (4-monthly to annual monitoring) and 'NICE conservative' (6-monthly to biennial monitoring). Two pathways differed in location (hospital and community), with monitoring biennially and treatment initiated

for a  $\geq 6\%$  5-year glaucoma risk. The ‘treat all’ pathway involved treatment with lowering pressure eye drops and annual intraocular pressure testing in the community.

**Results:** The ‘treat all’ strategy had the lowest average cost. Whilst hospital based active monitoring was the second most costly strategy, it was the only pathway with a positive average net-benefit (£452) – a finding partly explained by preferences to be actively monitored and reduced chance of having unwanted effects of treatment (compared to treat all). For the CUA hospital based active monitoring produced the highest average QALYs, the incremental cost per additional QALY (£85,312) was above NICE’s recommendation threshold (£30,000). The CUA suggested the ‘treat all’ strategy was the most cost-effective strategy.

**Conclusion:** These results suggest the results generated from CBA and CUA may be different - the question of what is the objective of a health care system is therefore important. Issues raised when incorporating DCE results into an economic model will be discussed.

## 14:45-15:30 Session 4

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### Societal Willingness-to-Pay for Hemophilia Therapies in the US

**Shraddha Shankarrao Chaugule, B.Pharm.Sc, MS**, University of Southern California, United States; **Joel Hay, PhD**, University of Southern California, United States; **Guy Young, MD**, Children’s Hospital of Los Angeles, University of Southern California Keck School of Medicine, United States

**Background and Objective:** The U.S. Centers for Disease Control estimates that there are an estimated 20,000 to 25,000 hemophiliacs in the US. There are two main strategies for hemophilia patients: on-demand (as needed therapy) and prophylaxis (preventive therapy). Thirty percent of the hemophilia patients in the US receive prophylactic factor replacement. The average annual cost of this treatment is ~3 times more than as-needed treatment. In a randomized controlled trial comparing these treatment modalities, Manco-Johnson noted that the cost of preventive treatment can reach as high as \$300,000 per year though preventive treatment provides improved health-related outcomes and quality of life. The objective of this study was to assess the relative importance of different treatment strategies for hemophilia in monetary terms in the US using the discrete choice experiment method to estimate willingness-to-pay in a representative sample of the US adult population. The rationale for asking the general population was that on average, 39% of the hemophilia patients in the US are on government-funded programs which pay for their expensive treatment and thus treatment costs are shared by the general population.

**Methods:** RAND Corporation’s American Life Panel has been extensively used in academic research. It uses sampling weights based on population characteristics in the current population survey, a monthly survey of US households conducted by the Census Bureau for the Bureau of Labor Statistics. For the pilot study, 6 panel members were interviewed over the phone. For the final survey, 235 panel members completed the survey. The discrete choice survey part presented a series of 5 trade-off questions consisting of hypothetical treatment profiles to each of the respondents. Respondents also had the option to opt-out of treatment for each of the scenarios. The relative importance of treatment attributes was analyzed using the nested logit model. Based on the attribute estimates, WTP was determined. A sensitivity analysis was also conducted to quantify the effect of excluding the respondents who fail rationality check. All analyses were performed using Stata version 13.0 (Stata Corporation, College Station, TX, 1997).

**Results:** Costs (p value <0.002), treatment efficacy & dosing frequency (p value <0.02) and treatment related complications (p <0.015) were perceived to be the most important attributes while making a treatment decision. The general population was willing-to-pay an additional \$530 per month out-of-pocket (95% CI: \$403; \$657) for three times weekly preventive therapy compared to as needed therapy. Key results also suggest that the US population was willing-to-pay an additional \$187 (95% CI: \$79; \$295) for improvement in dosing from 3 times weekly preventive treatment to once weekly preventive treatment.

**Conclusions:** The representatives of the community value clinical attributes such as treatment efficacy &



dosing frequency and treatment related complications while making a treatment decision for hemophilia population. However, the WTP results of this study suggest that it is unlikely the representatives of the community would consider preventive therapy to be cost effective.

### Treatment Preferences of Patients with Metastatic Non-Small Cell Lung Cancer: A Discrete Choice Experiment

**Axel C. Mühlbacher, PhD, MBA, and Susanne Bethge, MSc, BSc, Hochschule Neubrandenburg, Germany**

**Purpose:** Lung cancer is a major cause of cancer-related deaths and thus represents a global health problem. To date, decisions on which treatment to use are often driven by healthcare professionals' opinions. The perspective of patients with metastatic non-small cell lung cancer (NSCLC) on the importance of different treatment criteria and the ranking of these decision criteria are rarely taken into consideration. Aim of the study is the evaluation of patients' preferences for different treatment characteristics of NSCLC patients.

**Methods:** The literature review and 10 qualitative interviews revealed seven patient-relevant treatment attributes. A Discrete-Choice Experiment (DCE) was used to rank the patient-relevant treatment characteristics. The DCE was conducted using a fractional factorial design (Ngene) and the statistical data analysis used random effect logit and GLLAMM latent class models for subgroup identification.

**Results:** Within the qualitative part of this study (literature review and 10 qualitative interviews) seven patient-relevant treatment attributes could be identified. These attributes encompass outcome measures related to efficacy and side effects as well as the mode of administration. In total N=211 patients with metastatic NSCLC participated in the computer-assisted personal interviews. The estimation revealed a clear dominance for "progression-free survival" (coef.: 1.087) and "tumor-associated symptoms"(cough, shortness of breath and pain) (coef.: 1.090), followed by the side effects: "nausea and vomiting" (coef.: 0.605), "rash" (coef.: 0.432), "diarrhea" (coef.: 0.427) and "tiredness and fatigue" (coef.: 0.423). The "mode of administration" was less important for participants (coef.: 0.141).

**Conclusions:** "Progression-free survival" and "tumor-associated symptoms" were identified as key patient-relevant treatment characteristics in this study. The sole consideration of the "progression-free survival" as foundation for decisions is not sufficient from the patients' perspective and multiple criteria are important. Subgroup analysis revealed that the importance of "progression-free survival" increases with increased therapy experience. Basically, the results give insight into how much a deciding factor affects the treatment decision from the perspective of patients. In addition, the results of this survey can provide a basis for patient-oriented evaluation of treatment options in NSCLC.

## **BUSINESS AGENDA**

1. Opening and agenda: Axel C. Mühlbacher, Meeting Chair
2. Memorial to Ely Dahan, PhD
3. Financial report
4. Membership report
5. Announcements of future meetings
6. Discussion on sustainability
7. Closing

## ATTENDEES

<b>Susanne Bethge<sup>β</sup></b> Hochschule Neubrandenburg Germany	<b>Juan Marcos González<sup>α</sup></b> RTI Health Solutions United States
<b>John Bridges<sup>α</sup></b> Johns Hopkins Bloomberg School of Public Health United States	<b>Karin Groothuis-Oudshoorn<sup>α</sup></b> University of Twente The Netherlands
<b>Henk Broekhuizen<sup>β</sup></b> University of Twente The Netherlands	<b>Joel Hay<sup>α</sup></b> University of Southern California United States
<b>Shraddha Chaugule<sup>β</sup></b> University of Southern California United States	<b>Rodolfo Hernández<sup>β</sup></b> University of Aberdeen United Kingdom
<b>Benjamin Craig<sup>α</sup></b> Moffitt Cancer Center United States	<b>Mickaël Hiligsmann</b> Maastricht University The Netherlands
<b>Marion Danner<sup>β</sup></b> Institute for Health Economics and Clinical Epidemiology Germany	<b>Michał Jakubczyk</b> Warsaw School of Economics Poland
<b>Esther De Bekker-Grob<sup>α</sup></b> Erasmus MC - University Medical Centre Rotterdam The Netherlands	<b>Ellen Janssen<sup>β</sup></b> United States
<b>Domino Determann<sup>β</sup></b> National Institute of Public Health & the Environment (RIVM) The Netherlands	<b>Sarah Janus<sup>β</sup></b> University of Twente The Netherlands
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<b>Terry Flynn<sup>α</sup></b> University of Western Sydney Australia	<b>Christin Juhnke<sup>β</sup></b> Hochschule Neubrandenburg Germany

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<b>Andrea Libório<sup>β</sup></b> Instituto Nacional de Cardiologia Brasil	<b>Katharina Schmidt<sup>β</sup></b> IVBL, Leibniz Universität Hannover Germany
<b>Axel Mühlbacher<sup>α</sup></b> Hochschule Neubrandenburg Germany	<b>Ulrike Schmidt</b> Boehringer Ingelheim Pharma GmbH & Co. KG Germany
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<b>Mark Oppe<sup>α</sup></b> EuroQol Group The Netherlands	<b>Amy Shi</b> SAS Institute Inc. United States



<b>Fern Terris-Prestholt</b> London School of Hygiene and Tropical Medicine United Kingdom	<b>Elly Stolk<sup>α</sup></b> Institute for Medical Technology Assessment The Netherlands
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<sup>α</sup> Members

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## CURRENT IAHPR MEMBERS

<b>Esther de Bekker-Grob*</b>	<b>Christine Kistler</b>
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<b>Meenakshi Bewtra</b>	<b>Deborah Marshall</b>
<b>Abhijeet Bhanegaonkar</b>	<b>Ateesha Mohamed</b>
<b>John Bridges*</b>	<b>Axel Mühlbacher*</b>
<b>Derek Brown</b>	<b>Mark Oppe*</b>
<b>Margaret Byrne</b>	<b>Jan Ostermann</b>
<b>Benjamin M. Craig*</b>	<b>Christine Poulos</b>
<b>Terry Flynn*</b>	<b>Lisa Prosser</b>
<b>Liana Fraenkel</b>	<b>Shelby Reed*</b>
<b>Juan Marcos González*</b>	<b>Dean Regier</b>
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<b>Sarah Hawley</b>	<b>Elly Stolk*</b>
<b>Joel Hay*</b>	<b>Jamie Studts</b>
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<b>Joel Huber</b>	<b>Leslie Wilson*</b>
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\* Attending

# International Academy of Health Preference Research

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### Biosketch

Brief summary of research over the last five years

More insight into patients' preferences for medical interventions and economic evaluations is needed as a response to the strong push towards personalized medicine as well as dealing with scarcity in the allocation of healthcare require. In the last 5 years, Dr. Esther de Bekker-Grob's research has contributed to these issues using 1) an innovative quantitative approach to measure patients' preferences for medical interventions: discrete choice experiment (DCE), 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 20) medical topics in primary healthcare, clinical care as well as public health, and gave insight into the importance of (characteristics of) specific medical interventions, the trade-offs that patients make between them, probabilistic predictions about their resulting choice behaviour, and the costs and cost-effectiveness of medical interventions. Additionally, Dr. Esther de Bekker-Grob addressed methodological issues focusing on designing, modelling and validation of DCEs in healthcare. Furthermore, she has worked with many clinicians from various departments of different hospitals, mostly to address questions related to patients' preferences or economic evaluation. Recently, Dr. Esther de Bekker-Grob is also involved as a DCE-expert in studies from other national and international non-profit and profit organisations.

### Areas of Interest:

- |                                                                                           |                                                                                                                 |
|-------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| <input checked="" type="checkbox"/> Preferences Between Health-Related Goods and Services | <input checked="" type="checkbox"/> Preference Methods (Elicitation Tasks and Econometrics)                     |
| <input checked="" type="checkbox"/> Preferences Between Health Outcomes                   | <input checked="" type="checkbox"/> Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs) |

# International Academy of Health Preference Research

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## Biosketch

John is an associate professor in the Departments of Health Policy and Management and International Health at the Johns Hopkins Bloomberg School of Public Health, a Faculty Research Fellow at the National Bureau of Economic Research (NBER), New York, and a Senior Fellow at the Center for Medicine in the Public Interest. John's research is focused on the application of both qualitative and quantitative stated-preference methods to document the priorities and preferences of patients and other stakeholders in medicine. In addition to publishing over 80 peer-reviewed publications, he has made several important contributions to preference measurement in medicine. In 2008 he founded The Patient – Patient Centered Outcomes Research as the first journal in medicine to focus exclusively on the patients' perspective. John was also on the organizing committee for the first Conjoint Analysis and Health Conference (CHAC) in 2007, and went on to chair subsequent CHAC meeting in 2009, 2010, and 2012. At the International Society of Pharmacoeconomics and Outcomes Research (ISPOR) he founded the Patient Preference Methods/Conjoint Analysis working group (2006-2011), which led to the establishment of a series of methodological task-forces, including the "Good Research Practices for Conjoint Analysis Task Force" (2008-2010), which John chaired and which lead to the "ISPOR checklist for the application of conjoint analysis methods"; the "Conjoint Analysis Experimental Design Task Force" (2010-2012), and the "Conjoint Analysis Statistical Methods Task Force" (2013- ). In 2006 he received ISPOR's Bernie O'Brien New Investigator Award and in 2011 received an ISPOR Distinguished Service Award for his leadership of conjoint analysis methods.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)



# International Academy of Health Preference Research

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## Biosketch

Benjamin M. Craig, Ph.D., is an Associate Member in Health Outcomes and Behavior at Moffitt Cancer Center and Associate Professor of Economics at the University of South Florida. He received his M.S. in Economics at the University of Texas at Austin in 1999 and his Ph.D. in Population Health from the University of Wisconsin in 2003. His research focuses on health valuation and the economics of cancer prevention, detection, and control. Dr. Craig is currently the Principal Investigator for the PROMIS valuation project that will value PROMIS-29 v1.0 outcomes from both a societal perspective and a cancer survivor perspective. He is a member of the American Society of Clinical Oncology (ASCO), the International Health Economics Association (iHEA), the American Society of Health Economist (ASHE), the International Society for Pharmacoeconomics & Outcomes Research (ISPOR) and EuroQol Group.

## Areas of Interest:

- ▣ Preferences Between Health-Related Goods and Services
- ▣ Preference Methods (Elicitation Tasks and Econometrics)
- ▣ Preferences Between Health Outcomes
- ▣ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

# International Academy of Health Preference Research

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## Biosketch

I am a health economist with specialist skills in:

- (1) methodological issues - in discrete choice modelling and best-worst scaling in particular, and
- (2) applied areas such as quality of life - largely implementing the Capabilities Approach of Amartya Sen - and end-of-life care. Specifically:

I am a recognised world expert in best-worst scaling (BWS), with a particular interest in its use in health care and public policy. Together with the inventor, Professor Jordan Louviere, and Professor Anthony Marley, we are completing the definitive book explaining its use, to be published by Cambridge University Press in 2014. I have also published articles explaining the issues in conceptualising traditional valuation tasks within a random utility framework.

I am also co-developer of the ICECAP-O Capabilities quality of life (well-being) instrument, together with Professor Joanna Coast from the University of Birmingham. My website provides a link to a video of a public lecture of mine presenting results of its use in Australia, also showing why it beats "experienced utility" (aka life satisfaction / happiness scales).

As of March 2014 (according to google scholar - which picks up the cross-disciplinary citations to BWS that traditional bibliometrics do not) I have 1408 citations, an h-index of 22 and i-10 index of 33, all from only approximately 50 published journal papers and chapters. I have also had substantial influence on policy - my work on BWS influenced the valuation methods desired by the UK government in the field of social care.

## Areas of Interest:

- |                                                                                           |                                                                                                                 |
|-------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
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# International Academy of Health Preference Research

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## Biosketch

Juan Marcos González, PhD, is a Senior Research Economist at RTI HS. Dr. González has 8 years of experience in academic research in health and environmental economics. His areas of expertise are econometrics and discrete-choice analysis of revealed- and stated-preference data. In health economics, Dr. González has worked with discrete-choice experiments to investigate patients' and physicians' treatment preferences in several therapeutic areas, including cancer, psoriasis, and vaccine-preventable diseases. He currently is part of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Conjoint Analysis–Statistical Analysis, Reporting, and Conclusions (CA-SARC) Task Force. In environmental economics, Dr. González developed valuation models that bring together revealed- and stated-preference data to deal with shortcomings of each data type. These models have been used to assess the value of access to recreational sites in El Yunque National Forest (formerly Caribbean National Forest), Puerto Rico, and for similar valuation efforts along the Snake River area in Jackson Hole, Wyoming, and Off-Highway Vehicles Parks in North Carolina. Dr. González's work has been published in peer-reviewed journals, including *Headache*, *Vaccine*, *Social Science & Medicine*, *Value in Health*, and *Journal of Patient Preference and Adherence*, as well as a textbook on preference valuation in environmental economics: *Preference Data for Environmental Valuation: Combining Revealed and Stated Approaches*.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

# International Academy of Health Preference Research

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## Biosketch

Dr C.G.M. Groothuis-Oudshoorn has 15 years of experience as a (registered) biostatistician in health services research at several research institutes. After working for several years at TNO Quality of Life (Leiden) and Roessingh Research and Development (Enschede) she is now an assistant professor at the University of Twente, department of Health Technology and Services Research. She has broad research experience in development and analysis of discrete choice experiments. She is a member of the ISPOR Conjoint analysis – Statistical analysis, results & conclusions good research practices task force.

At the moment her research focuses on: analysis of discrete choice experiments, best-worst scaling, uncertainty in MCDA for healthcare, heterogeneity in preferences and multiple imputation.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)



# International Academy of Health Preference Research

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## Biosketch

Joel W. Hay is Professor and Founding Chair in the Department of Pharmaceutical Economics and Policy in the School of Pharmacy and a Professor of Health Policy and Economics in the Leonard Schaeffer Center for Health Policy and Economics, with a joint appointment in the Department of Economics at the University of Southern California. He also serves as the USC Project Coordinator for the Rand Evidence-Based Medicine Practice Centers of Southern California funded by the US Agency for Health Research and Quality (AHRQ). He is a Health Economics Research Scholar at the UCLA Center for Vaccine Research. He is a founding member and founding Executive Board member of the American Society for Health Economics (ASHEcon) and of the International Society for Pharmaceutical Economics and Outcomes Research (ISPOR).

His previous positions include: Senior Research Fellow, the Hoover Institution, Stanford University (1985-1992); Senior Policy Analyst, Project HOPE (1983-1985); Asst. Professor, Dept. of Behavioral Sciences and Community Health, and Dept. of Economics, University of Connecticut (1980-1984); and Asst. Research Professor, University of Southern California (1978-1980). He received his B.A. summa cum laude from Amherst College in 1974 and his M.A. (1975), M. Ph. (1976) and Ph.D. in economics (1980) from Yale University.

Dr. Hay has authored or coauthored over 400 peer-reviewed scientific articles, abstracts, editorials and reports in the fields of pharmaceutical economics, health economics, outcomes research, disease management, statistics, econometrics, epidemiology and health care in journals including more than 170 peer-reviewed scientific articles in journals such as: American Journal of Cardiology, American Journal of Health-Systems Pharmacy, American Journal of Managed Care, American Journal of Public Health, Archives of Neurology, Cancer, Community Dentistry and Oral Epidemiology, General Dentistry, Haemophilia, Health Care Financing Review, Health Economics, Health Policy, JAMA, Journal of AIDS, Journal of the American Geriatrics Society, Journal of Business & Economic Statistics, Journal of Clinical Gastroenterology, Journal of Health Economics, Journal of Health Politics, Policy and Law, Journal of Human Resources, and more.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

# International Academy of Health Preference Research

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## Biosketch

F. Reed Johnson has more than 35 years of academic and research experience in health and environmental economics. He has served on the faculties of several universities in the United States, Canada, and Sweden and as Distinguished Fellow at Research Triangle Institute. He currently is Senior Research Scholar in the Duke University School of Medicine. As a staff member in the US Environmental Protection Agency's environmental economics research program during the 1980s, Dr. Johnson helped pioneer development of basic non-market valuation techniques. These techniques are now widely used for cost-benefit analysis in health and environmental economics. He has designed and analyzed numerous surveys for measuring preferences for and value of health outcomes, health-risk reductions, and improved environmental quality.

Dr. Johnson has over 120 publications in books and peer-reviewed journals. His research has been published in various medical journals, the Review of Economics and Statistics, Journal of Health Economics, Medical Decision Making, Health Economics, Value in Health, Journal of Policy Analysis and Management, and other journals. He has coauthored a book on techniques for using existing environmental and health value estimates for policy analysis. His current research involves estimating general time equivalences among health states and patients' willingness to accept side-effect risks in return for therapeutic benefits. He recently completed the first FDA-sponsored study to quantify patients' willingness to accept benefit-risk tradeoffs for new health technologies. The results are being used to inform reviews of regulatory submissions.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

# International Academy of Health Preference Research

**Surname (Last):** Mühlbacher

**Given Name:** Axel

**Degrees:** PhD

**Institution:** IGM Institute Health Economics and Health Care Management

**Position:** Professor of Health Economics and Health Care Management

**Address:** Hochschule Neubrandenburg  
IGM Institut Gesundheitsökonomie und Medizinmanagement  
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**ZIP Code:** 17033 **State/Province/Region:** Mecklenburg-Vorpommern

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## Biosketch

Axel Mühlbacher, Dr. rer. oec., Dipl.-Kfm., is professor of health economics and health care management at the Hochschule Neubrandenburg. Since 2012 he is 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 placed at Duke Clinical Research Institute and Fuqua School of Business, Duke University. His research focuses on patient preferences, comparative effectiveness / economic evaluation methods and organized health care system. He also is an economist at the Center of Innovative Health Technologies (ZIG), Technical University Berlin and a member at the Berlin School of Public Health, Charité Berlin.

In 1996 he graduated from the Eberhard-Karls University, Tübingen, where he had earned a degree in business administration and economics. In 1996 he was appointed as 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 TU Berlin, HU, FU 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). Prior to founding the Institute of Health Economics and Health Care Management at Hochschule Neubrandenburg in 2006, Dr. Mühlbacher had been an assistant professor at the department of economics and management at Technical University Berlin (2001-2004) and associate professor of economics, health economics and econometrics (C2) at Hochschule Neubrandenburg (2004-2006).

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)



# International Academy of Health Preference Research

**Surname (Last):** Oppe

**Given Name:** Mark

**Degrees:** PhD, MSc

**Institution:** EuroQol Group

**Position:** Senior Scientist

**Address:** Marten Meesweg 107

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**ZIP Code:** 3068 AV **State/Province/Region:** South Holland

**Country:** The Netherlands

**Phone:** +31 88 440-0190

**Fax:**

**Email:** oppe@euroqol.org

**Website:** www.euroqol.org



## Biosketch

After obtaining his masters degree in astrophysics in 2001 at Utrecht University, Mark started to work in health economics as a researcher for the Centre for Health Policy and Law of Erasmus University Rotterdam. During this time he carried out various projects on End Stage Renal Disease and on Quality of Life measurement (the latter on behalf of the EuroQol Group Executive Office). In 2005 he joined the institute for Medical Technology Assessment of Erasmus University Rotterdam. The focus of his work at IMTA was on quantitative research, in particular on probabilistic Markov modelling, meta-analyses techniques and mathematics. While at IMTA about 40% of his research projects were carried out on behalf of the EuroQol Group Executive Office. He obtained his PhD at Erasmus university in May 2013, based on the combination of work done for IMTA and for the EuroQol Group. Since November 2012 Mark has a full time position as senior researcher at the EuroQol Group Executive Office. His work for the EuroQol Group centres on elicitation and modelling techniques to obtain utility values with EQ-5D. In particular he was involved in the management and development of the valuation protocol and software for the valuation of the EQ-5D-5L.

## Areas of Interest:

- |                                                                                                                                           |                                                                                                                                                                 |
|-------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
|  Preferences Between Health-Related Goods and Services |  Preference Methods (Elicitation Tasks and Econometrics)                     |
|  Preferences Between Health Outcomes                   |  Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs) |

# International Academy of Health Preference Research

**Surname (Last):** Reed

**Given Name:** Shelby

**Degrees:** PhD, RPh

**Institution:** Duke Clinical Research Institute

**Position:** Professor

**Address:** 2400 Pratt Street

**City:** Durham

**ZIP Code:** 27705 **State/Province/Region:** North Carolina

**Country:** USA

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**Email:** shelby.reed@dm.duke.edu

**Website:** www.duke.edu



## Biosketch

Shelby D. Reed, PhD, RPh, is a Professor in the School of Medicine at Duke University in Durham, NC. Her primary appointment is in the Duke Clinical Research Institute where she leads numerous studies in economic evaluation, health services research and health policy. Dr. Reed has extensive expertise in designing and conducting trial-based and model-based cost-effectiveness analyses of medical diagnostics and interventions in cancer, cardiovascular disease, cerebrovascular disease, diabetes, infectious disease, pulmonology, and other conditions. In addition, she has performed numerous economic and epidemiological studies using secondary data from health care claims and disease registries. In her evaluations of health policy issues, she has developed computer models to analyze the potential economic impact of trends in clinical trial design, changes in reimbursement policies, financial incentives and the regulatory process in the development of orphan drugs, and the societal value of alternative approaches to identifying drug safety problems. Areas of current focus are conjoint analysis and multicriteria decision analysis, in which she is engaged in studies in health care delivery, cancer, medicine and orthopedics.

## Areas of Interest:

- |                                                                                           |                                                                                                                 |
|-------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| <input checked="" type="checkbox"/> Preferences Between Health-Related Goods and Services | <input checked="" type="checkbox"/> Preference Methods (Elicitation Tasks and Econometrics)                     |
| <input checked="" type="checkbox"/> Preferences Between Health Outcomes                   | <input checked="" type="checkbox"/> Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs) |



# International Academy of Health Preference Research

**Surname (Last):** Ryan

**Given Name:** Mandy

**Degrees:** PhD, MSc, BA

**Institution:** University of Aberdeen

**Position:** Professor

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## Biosketch

Mandy is the Director of the Health Economics Research Unit (HERU) at the University of Aberdeen. She joined HERU in 1987 after graduating from the University of Leicester with a BA (Hons) in Economics and the University of York with an MSc in Health Economics. In 1995 she graduated from the University of Aberdeen with a PhD in Economics concerned with the application of contingent valuation and discrete choice experiments in health economics. In 1997 Mandy was awarded a 5-year MRC Senior Fellowship to develop and apply discrete choice experiments in health care, in 2002 she was awarded a Personal Chair in Health Economics by the University of Aberdeen and in 2006 she was elected as a Fellow of the Royal Society of Edinburgh. She was a member of the RAE 2008 sub-panel 7 (Health Services Research) and is currently a member of the MRC Methodology Research Panel and Strategic Skills panel. Mandy took up the Directorship of HERU in April 2013. Professor Ryan has worked with academics, government and the pharmaceutical industry and has published widely in the field of health economics generally, and monetary valuation more specifically. Professor Ryan also has extensive teaching experience, and contributes to HERU's MSc Economics of Health.

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

# International Academy of Health Preference Research

**Surname (Last):** Stolk  
**Given Name:** Elly  
**Degrees:** PhD  
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**Position:** Assistant Professor  
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## Biosketch

I am assistant professor at the institute of health policy and management of Erasmus University Rotterdam, where I have an appointment since 1997. My main interests are in the measurement of individual and social preferences for informing health care decision-making. This includes social and patient preferences for health and non health outcomes. I have more than 15 years experiences in capturing these preferences using methods like TTO, and DCE (in- and outside healthcare). I have published widely in the area (more than 50 publications).

## Areas of Interest:

- |                                                                                           |                                                                                                                 |
|-------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| <input checked="" type="checkbox"/> Preferences Between Health-Related Goods and Services | <input checked="" type="checkbox"/> Preference Methods (Elicitation Tasks and Econometrics)                     |
| <input checked="" type="checkbox"/> Preferences Between Health Outcomes                   | <input checked="" type="checkbox"/> Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs) |

# International Academy of Health Preference Research

**Surname (Last):** Wilson

**Given Name:** Leslie

**Degrees:** PhD

**Institution:** University of California San Francisco

**Position:** Professor

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**Website:**



## Biosketch

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

## Areas of Interest:

- ☒ Preferences Between Health-Related Goods and Services
- ☒ Preference Methods (Elicitation Tasks and Econometrics)
- ☒ Preferences Between Health Outcomes
- ☒ Preference Tools and Technologies (Calculators, Decision Aids, and Tariffs)

## **UPCOMING IAHPR MEETINGS**

### **2nd Meeting of the International Academy of Health Preference Research**

Tuesday, 29 September 2015, 8:00-17:30, chaired by Emily Lancsar  
Cliftons Brisbane  
Level 3, 288 Edward Street  
Brisbane, Queensland, Australia 4000  
[www.cliftons.com](http://www.cliftons.com)

### **3rd Meeting of the International Academy of Health Preference Research**

Sunday, 18 October 2015, 8:00-17:30, chaired by Derek Brown  
Charles F. Knight Executive Education & Conference Center  
1 Bookings Drive  
St. Louis, Missouri, USA 63130  
[www.acc-knightconferencecenter.com](http://www.acc-knightconferencecenter.com)

### **4th Meeting of the International Academy of Health Preference Research (Tentative)**

Wednesday, 13 July 2016, 8:00-17:30, chaired by Mandy Ryan and Elly Stolk  
TBD, Hamburg, Germany

### **5th Meeting of the International Academy of Health Preference Research (Tentative)**

Saturday, 3 September 2016, 8:00-17:30, chaired by Kirsten Howard and Mark Oppe  
TBD, Singapore

### **6th Meeting of the International Academy of Health Preference Research (Tentative)**

Friday, 7 July 2017, chaired by Juan Marcos González and TBD  
TBD, Boston, Massachusetts, USA

### **7th Meeting of the International Academy of Health Preference Research (Tentative)**

November 2017, chaired by TBD  
TBD, Glasgow, Scotland, UK



### Educational Publications in Health Preference Research

The first section provides lists of publications that meet two criteria: (1) the publication is focused on education (no original articles, evaluations or commentaries); and (2) pertain solely to either health or health-related preferences (primary data; no instruments, decision aids, or tariffs). The second section provides lists of reference textbooks that may aid health preference researcher, but pertain to broader interests (e.g., choice defines value). Each list is shown in chronological order (newest first) to favor more recent publications. If you have additions, please send them to [info@iahpr.org](mailto:info@iahpr.org).

### SECTION 1: Health Preferences

#### General Literature Review

1. Harrison M, Rigby D, Vass C, Flynn T, Louviere J, Payne K. Risk as an attribute in discrete choice experiments: A systematic review of the literature. *The patient*. 2014; 7(2):151-170.
2. Clark MD, Determann D, Petrou S, Moro D, de Bekker-Grob EW. Discrete choice experiments in health economics: A review of the literature. *PharmacoEconomics*. 2014; 32(9):883-902.
3. Naik-Panvelkar P, Armour C, Saini B. Discrete choice experiments in pharmacy: a review of the literature. *The International journal of pharmacy practice*. 2013; 21(1):3-19.
4. Mühlbacher AC, Juhnke C. Patient preferences versus physicians' judgement: does it make a difference in healthcare decision making? *Applied health economics and health policy*. 2013; 11(3):163-180.
5. Johnson FR, Lancsar E, Marshall D, et al. Constructing Experimental Designs for Discrete-Choice Experiments: Report of the ISPOR Conjoint Analysis Experimental Design Good Research Practices Task Force. *Value in Health*. 2013; 16(1):3-13.
6. Wicher CP, Meeker MA. What influences African American end-of-life preferences? *Journal of health care for the poor and underserved*. 2012; 23(1):28-58.
7. de Bekker-Grob EW, Ryan M, Gerard K. Discrete choice experiments in health economics: A review of the literature. *Health Economics*. 2012; 21(2):145-172.
8. Tilling C, Devlin N, Tsuchiya A, Buckingham K. Protocols for time tradeoff valuations of health states worse than dead: a literature review. *Medical decision making: an international journal of the Society for Medical Decision Making*. 2010; 30(5):610-619.
9. Marshall D, Bridges JFP, Hauber B, et al. Conjoint Analysis Applications in Health - How are Studies being Designed and Reported? An Update on Current Practice in the Published Literature between 2005 and 2008. *Patient-Patient Centered Outcomes Research*. 2010; 3(4):249-256.
10. Flynn TN. Valuing citizen and patient preferences in health: Recent developments in three types of best-worst scaling. *Expert Review of Pharmacoeconomics & Outcomes Research*. 2010; 10(3):259-267.
11. Lagarde M, Blaauw D. A review of the application and contribution of discrete choice experiments to inform human resources policy interventions. *Human Resources for Health*. 2009; 7.
12. Lancsar E, Louviere J. Conducting discrete choice experiments to inform Healthcare decision making. *PharmacoEconomics*. 2008; 26(8):661-677.
13. Lancsar E, Louviere J. Deleting 'irrational' responses from discrete choice experiments: a case of investigating or imposing preferences? *Health Economics*. 2006; 15(8):797-811.
14. Bridges JF. Stated preference methods in health care evaluation: An emerging methodological paradigm in health economics. *Applied health economics and health policy*. 2003; 2(4):213-224.

#### Disease-Specific Literature Review

1. Purnell TS, Joy S, Little E, Bridges JFP, Maruthur N. Patient Preferences for Noninsulin Diabetes Medications: A Systematic Review. *Diabetes Care*. 2014; 37(7):2055-2062.
2. Sung L, Regier DA. Decision Making in Pediatric Oncology: Evaluation and Incorporation of Patient and Parent Preferences. *Pediatric Blood & Cancer*. 2013; 60(4):558-563.



3. McHugh RK, Whitton SW, Peckham AD, Welge JA, Otto MW. Patient preference for psychological vs pharmacologic treatment of psychiatric disorders: a meta-analytic review. *The Journal of clinical psychiatry*. 2013; 74(6):595-602.
4. Kang S, O'Reilly M, Lancioni G, Falcomata TS, Sigafoos J, Xu Z. Comparison of the predictive validity and consistency among preference assessment procedures: a review of the literature. *Research in developmental disabilities*. 2013; 34(4):1125-1133.
5. Joy SM, Little E, Maruthur NM, Purnell TS, Bridges JFP. Patient Preferences for the Treatment of Type 2 Diabetes: A Scoping Review. *PharmacoEconomics*. 2013; 31(10):877-892.
6. Franco MR, Ferreira ML, Ferreira PH, Maher CG, Pinto RZ, Cherkin DC. Methodological limitations prevent definitive conclusions on the effects of patients' preferences in randomized clinical trials evaluating musculoskeletal conditions. *Journal of clinical epidemiology*. 2013; 66(6):586-598.
7. Dahl L, Wittrup I, Vaeggemose U, Petersen LK, Blaakaer J. Life after gynecologic cancer—a review of patients quality of life, needs, and preferences in regard to follow-up. *International journal of gynecological cancer: official journal of the International Gynecological Cancer Society*. 2013; 23(2):227-234.
8. Brooker AS, Carcone S, Witteman W, Krahn M. Quantitative patient preference evidence for health technology assessment: a case study. *International journal of technology assessment in health care*. 2013; 29(3):290-300.
9. Wong J, Szumacher E. Patients' decision-making in radiation oncology. *Expert Rev Pharmacoecon Outcomes Res*. 2012; 12(1):95-104.
10. Umar N, Yamamoto S, Loerbroeks A, Terris D. Elicitation and use of patients' preferences in the treatment of psoriasis: a systematic review. *Acta dermato-venereologica*. 2012; 92(4):341-346.
11. Sadique MZ, Legood R. Women's preferences regarding options for management of atypical, borderline or low-grade cervical cytological abnormalities: a review of the evidence. *Cytopathology: official journal of the British Society for Clinical Cytology*. 2012; 23(3):161-166.
12. MacLean S, Mulla S, Akl EA, et al. Patient values and preferences in decision making for antithrombotic therapy: a systematic review: Antithrombotic Therapy and Prevention of Thrombosis, 9th ed: American College of Chest Physicians Evidence-Based Clinical Practice Guidelines. *Chest*. 2012; 141(2 Suppl):e1S-23S.
13. Lin OS, Kozarek RA, Gluck M, et al. Preference for colonoscopy versus computerized tomographic colonography: a systematic review and meta-analysis of observational studies. *Journal of general internal medicine*. 2012; 27(10):1349-1360.
14. Kaimal AJ, Kuppermann M. Decision making for primary cesarean delivery: the role of patient and provider preferences. *Seminars in perinatology*. 2012; 36(5):384-389.
15. Frederiksen ME, Lynge E, Rebolj M. What women want. Women's preferences for the management of low-grade abnormal cervical screening tests: a systematic review. *BJOG: an international journal of obstetrics and gynaecology*. 2012; 119(1):7-19.
16. Dev S, Abernethy AP, Rogers JG, O'Connor CM. Preferences of people with advanced heart failure—a structured narrative literature review to inform decision making in the palliative care setting. *American heart journal*. 2012; 164(3):313-319 e315.
17. Blinman P, King M, Norman R, Viney R, Stockler MR. Preferences for cancer treatments: An overview of methods and applications in oncology. *Annals of Oncology*. 2012; 23(5):1104-1110.
18. van der Meer L, Sigafoos J, O'Reilly MF, Lancioni GE. Assessing preferences for AAC options in communication interventions for individuals with developmental disabilities: a review of the literature. *Research in developmental disabilities*. 2011; 32(5):1422-1431.
19. Morales AM, Casillas M, Turbi C. Patients' preference in the treatment of erectile dysfunction: a critical review of the literature. *International journal of impotence research*. 2011; 23(1):1-8.
20. Mazzoni A, Althabe F, Liu NH, et al. Women's preference for caesarean section: a systematic review and meta-analysis of observational studies. *BJOG: an international journal of obstetrics and gynaecology*. 2011; 118(4):391-399.

21. Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp K. Preferred and actual participation roles during health care decision making in persons with cancer: a systematic review. *Annals of oncology: official journal of the European Society for Medical Oncology / ESMO*. 2010; 21(6):1145-1151.
22. Emberton M. Medical treatment of benign prostatic hyperplasia: physician and patient preferences and satisfaction. *International journal of clinical practice*. 2010; 64(10):1425-1435.
23. Blinman P, Alam M, Duric V, McLachlan SA, Stockler MR. Patients' preferences for chemotherapy in non-small-cell lung cancer: a systematic review. *Lung cancer (Amsterdam, Netherlands)*. 2010; 69(2):141-147.
24. McCaughan E, Prue G, Parahoo K. A systematic review of quantitative studies reporting selected patient experienced outcomes, with a specific focus on gender differences in people with colorectal cancer. *European journal of oncology nursing: the official journal of European Oncology Nursing Society*. 2009;13(5):376-385.

#### Book Sections (Chapters or Parts)

1. Lancsar E, Burge P. Choice modelling research in health economics. In: Hess SDA, ed. *Handbook of Choice Modelling*. Cheltenham: Edward Elgar Publishing; 2014:675-687.
2. Tsuchiya A. Distributional judgments in the context of economic evaluation. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:406-414.
3. Smith R, Lorgelly P, Al-Janabi H, Venkatapuram S, Coast J. The capability approach: An alternative evaluation paradigm for health economics? In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:415-424.
4. Ryan M, Gerard K, Currie G. Using discrete choice experiments in health economics. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:437-446.
5. Feeny D. The multi-attribute utility approach to assessing health-related quality of life. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:383-394.
6. Donaldson C, Mason H, Shackley P. Contingent valuation in health care. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:425-436.
7. Burgess L, Street DJ, Viney R, Louviere J. Design of choice experiments in health economics. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:447-461.
8. Brazier J, Roberts J, Rowen D. Methods for developing preference-based measures of health. In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:395-405.
9. Bleichrodt H, Pinto JL. Conceptual foundations for health utility measurement. . In: Jones AM, ed. *The Elgar companion to health economics*. Cheltenham, UK; Northampton, MA: Edward Elgar; 2012:371-382.
10. Sox H, Blatt M, Higgins M, Marton K. Measuring the Outcome of Care. *Medical Decision Making*. 1st ed. Philadelphia: The American College of Physicians; 2007:167-200.
11. Vos T. The case against annual profiles for the valuation of disability weights. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:467-472.
12. Ustun B, Rehm J, Chatterji S. Are disability weights universal? Ranking of the disabling effects of different health conditions in 14 countries by different informants. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:581-592.
13. Sommerfeld J, Baltussen RMPM, Metz L, Sanon M, Sauerborn R. Determinants of variance in health state valuations. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:549-580.

14. Salomon JA, Murray CJL. A conceptual framework for understanding adaptation, coping and adjustment in health state valuations. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:619-625.
15. Salomon JA, Murray CJL. Estimating health state valuations using a multiple-method protocol. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:487-499.
16. Sadana R. Measurement of variance in health state valuations in Phnom Penh, Cambodia. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:593-618.
17. Mahapatra P, Salomon JA, Nanda L. Measuring health state values in developing countries: Results from a community survey in Andhra Pradesh. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:473-486.
18. Feeny D. The utility approach to assessing population health. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:515-528.
19. Essink-Bot M, Bonsel GJ. How to derive disability weights. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:449-466.
20. Dolan P. Modelling the relationship between the description and valuation of health states. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:501-514.
21. Brazier J, Rice N, Roberts J. Modelling health state valuation data. In: Murray CJL, ed. *Summary measures of population health concepts, ethics, measurement and applications*. Geneva: World Health Organization; 2002:529-547.
22. Dolan P. The measurement of health-related quality of life for use in resource allocation decisions in health care. In: Culyer AJ, Newhouse J, eds. *Handbook of Health Economics*. Vol 1A. New York: Elsevier; 2000.
23. Kaplan RM. Utility assessment for estimating quality-adjusted life years. In: Sloan FA, ed. *Valuing Health Care: Costs, Benefits, and Effectiveness of Pharmaceuticals and Other Medical Technologies*. New York: Cambridge University Press; 1995:31-60.

#### Published Proceedings

1. Scientific Plenary Meeting of the EuroQol Group - Proceedings. Rotterdam, the Netherlands: EuroQol Group Executive Office; 1991-2013.
2. Berg RL. Health Status Indexes: Proceedings of a Conference Conducted by Health Services Research, Tucson, Arizona, October 1-4, 1972. 1972; Tucson, Arizona.

#### Textbooks

1. Brooks RG. *The EuroQol Group after 25 Years*. New York: Springer; 2013.
2. McIntosh E, Clarke P, Frew EJ, Louviere JJ. *Applied Methods of Cost-Benefit Analysis in Health Care*. New York: Oxford University Press; 2010.
3. Ryan M, Gerard K, Amaya-Amaya M. *Using Discrete Choice Experiments to Value Health and Health Care*. Dordrecht: Springer; 2008.
4. Szende A, Oppe M, Devlin NJ. *EQ-5D Value Sets: Inventory, Comparative Review, and User Guide*. Vol 2. Dordrecht: Springer; 2007.
5. Brazier J, Ratcliffe J, Tsuchiya A, Salomon JA. *Measuring and Valuing Health Benefits for Economic Evaluation*. New York: Oxford University Press; 2007.
6. Kind P, Brooks RG, Rabin R. *EQ-5D Concepts and Methods: A Developmental History*. Dordrecht: Springer; 2005.

7. Brooks RG, Rabin R, De Charro F. *The Measurement and Valuation of Health Status Using EQ-5D: A European Perspective: Evidence form the EuroQol BIOMED Research Programme*. Boston: Kluwer Academic Publishers; 2003.
8. Johansson P. *Evaluating Health Risks: An Economic Approach*. New York: Cambridge University Press; 1995.
9. Tolley GS, Kenkel DS, Fabian RG. *Valuing Health for Policy: An Economic Approach*. Chicago: University of Chicago Press; 1994.
10. Patrick DL, Erickson P. *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation*. New York: Oxford University Press; 1993.
11. Mushkin SJ, Dunlop DW. *Health, What is it Worth?: Measures of Health Benefits*. New York: Pergamon Press; 1979.

## **SECTION 2: Reference Textbooks**

### Individual Choice Measurement

1. Louviere JJ, Flynn TN, Marley AAJ. *Best-Worst Scaling: Theory, Methods and Applications*. Cambridge: Cambridge University Press; 2014.
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## NOTES