

# The 11<sup>th</sup> Meeting of the International Academy of Health Preference Research

### Workshop & Symposium

### **Networking Dinner**

Monday, 2 December 2019 from 08:00 17:30 Monday, 2 December 2019 from 18:00 to 22:00

Chaired by **Richard De Abreu Lourenço** and **Elisabeth Huynh**, the 11<sup>th</sup> Meeting will be held at the Clifton Auckland as a forum to present and discuss innovative developments in health preference research.

On Monday, 2 December 2019, the Academy will host a **Workshop**, "Good practices in health preference research" led by **Benjamin M. Craig.** Starting at 8:00 in the morning (below), this workshop will describe the basics on how to conduct a health preference study. After the mid-morning break, attendees will be broken into groups and asked to assess an example study as a hands-on exercise. **Richard De Abreu Lourenço** and **Elisabeth Huynh** will then review examples of challenges faced while assessing preferences in marginalised groups. The workshop builds directly from the textbook under development by IAHPR members and incorporates the experiences of

After lunch, the Academy will host a **Symposium**, "Giving a voice to marginalised groups for health care reform." This symposium (next page) will be on the priorities of groups that are difficult to reach/neglected/outside of the mainstream in health policy. Specifically, it will focus on the preference evidence of four marginalised groups (adolescents and young adults [AYA]; lesbian, gay, bisexual, transgender, intersex and questioning [LGBTIQ]; members of indigenous populations; and persons with disabilities) and its implications for health care reform. In complement to advocacy and developing health policies that matter, having an understanding of their perspectives is an essential precursor to reforms that may better serve their social and health care needs. After the presentations by invited speakers, the panel will discuss key topics defined in advance by the co-chairs followed by a question and answer session.

After the symposium, the Academy will host a **Networking Dinner** at Culprit (12 Wyndham Street, around the corner from Cliftons; < 5 minute walk), including a brief welcome from **Emily Lancsar** on behalf of the IAHPR Foundation Board. We were able to book the entire restaurant and the dinner is included with registration for either the symposium, meeting or both (no guests, please).

On Tuesday, 3 December 2019, the Academy will host its full-day **Scientific Meeting** including peerreviewed podium presentations, lunch (with poster session), and a business session.

### MONDAY, 2 DECEMBER 2019

scientists working with the region.

Workshop, "Good practices in health preference research."
 Cliftons Auckland, Level 4, 45 Queen Street, Auckland, New Zealand
 Instructor: Benjamin M. Craig, Richard De Abreu Lourenço<sup>α</sup> and Elisabeth Huynh<sup>α</sup>

8:00-8:15	Arrival and Light Breakfast
8:15-9:45	Lecture
9:45-10:00	Morning Break
10:00-11:00	Hands-on exercise
11:00-12:00	Case discussion on symposium topic and regional issues
12:00-13:00	Workshop Lunch (Workshop attendees only)

### **Scientific Meeting**

Tuesday, 3 December 2019 from 08:00 17:30



**Cliftons Auckland** Level 4, 45 Queen Street, Auckland, New Zealand







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**Symposium,** "Giving a voice to marginalised groups for health care reform." Cliftons Auckland, Level 4, 45 Queen Street, Auckland, New Zealand Meeting Chairs: **Richard De Abreu Lourenço**<sup> $\alpha$ </sup> and **Elisabeth Huynh**<sup> $\alpha$ </sup>

### 13:00-13:15 Welcome

13:15-14:30 Session 1 - Working with Indigenous Populations

Different cultural perspectives in measuring and valuing health: a challenge for preference-weighted PROs, **Nancy Devlin** What Matters: Development of a measure of Aboriginal and Torres Strait Islander Wellbeing, **Kirsten Howard**  $^{\alpha}$ Interview discussion – **Esther Willing** 

### 14:30-14:45 Afternoon Break

14:45-16:00 Session 2 - Working with Marginalised Groups

Whose values in health? A comparison of adult and adolescent health state preferences for informing economic evaluation and policy in adolescent health, **Julie Ratcliffe**  $\alpha$ 

The Russian doll experience: recruiting subpopulations of "hidden" populations for discrete choice experiments in Australia, Hong Kong and Nigeria, **Jason Ong**  $^{\alpha}$ 

### Interview discussion – Jo Watson, Chris Carswell <sup>a</sup>

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

A panel of eight contributors will discuss their experiences on incorporating consumers in health preference research with insights on what has worked well, what doesn't work well, where there is scope for more and how they would like things to evolve. The discussion will conclude with an open question and answer session.

17:15-17:30 Concluding Remarks

### Networking Dinner, 18:00-22:00

Culprit, 12 Wyndham Street, Auckland, New Zealand (1 block from Cliftons) Chefs: Kyle Street, Jordan Macdonald

TUESDAY, 3 DECEMBER 2019

### **Scientific Meeting**

Cliftons Auckland, Level 4, 45 Queen Street, Auckland, New Zealand Meeting Chairs: **Richard De Abreu Lourenço**<sup> $\alpha$ </sup> and **Elisabeth Huynh**<sup> $\alpha$ </sup>

8:00-8:15 Arrival and Light Breakfast

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

8:30-10:00 Session 1

Patient preferences for approaches to cancer treatment - trading between quality of life and survival, **Alison Pearce**<sup> $\alpha$ </sup>

Community preferences for care at the end of life: the final three weeks with cancer, **Deborah Street**<sup> $\alpha$ </sup>

Exploring heterogeneity in moral terminology used by patients in palliative care consultations, **Eline van den Broek-Altenburg** 

10:00-10:30 Morning Break

10:30-12:00 Session 2

Eliciting quality-adjusted life years using the time trade off method for Prader-Willi syndrome, **John F. P. Bridges**<sup> $\alpha$ </sup>

Valuing EQ-5D-5L: comparing the time trade off and discrete choice experiment valuation methods, **Brendan Mulhern**<sup> $\alpha$ </sup> Peruvian valuation of the EQ-5D-5L: a direct comparison of TTO and DCE, **Benjamin M. Craig**<sup> $\alpha$ </sup>

12:00-13:15 Lunch and Group Photo

13:15-14:45 Session 3

Does combining data from the laboratory with a DCE improve our understanding of decision-making? **Emily Lancsar**<sup>α</sup> Whose priorities matter? comparing patient and societal preferences for type 2 diabetes outcomes, **Sarah Janse** Eliciting relative importance of subjective wellbeing dimensions: empirical comparisons of 4 methods, **Gang Chen**<sup>α</sup> 14:45-15:00</sup> Afternoon Break

15:00-16:30 Session 4

Patient preferences for provider choice: a discrete choice experiment, Adam Atherly

Does the price premium for branded medicines reflect preferences? A case study from Australia, **Elena Mechcheriakova** Pharmacist preferences for prescribing models in primary care in NZ: a discrete choice experiment, **Rakhee Raghunandan** 16:30-17:30 Business Session (All attendees are welcome)

<sup>a</sup> indicates an IAHPR member







### 11TH MEETING OF THE INTERNATIONALACADEMY OF HEALTH PREFERENCE RESEARCH

#### Emily Lancsar

Australian National University, Canberra, Australia

Established on 15 April 2014, the International Academy of Health Preference Research (IAHPR) is a member-driven, inter-generational organization that promotes educational activities and research with respect to health and health-related preferences. Our aim is to improve decisions about health and healthcare throughout the world by developing, promoting, and supporting health preference research with the widest possible applicability.

The 11th Meeting will be held on Monday and Tuesday, 2–3 December 2019, and chaired by Richard De Abreu Lourenço and Elisabeth Huynh. The workshop, symposium and scientific meeting will be held at Cliftons, Auckland, New Zealand.

Starting at 8:00 on Monday, 2 December 2019, the Academy will host a workshop on "Good practices for health preference research" led by Benjamin M. Craig. The morning workshop will start by describing the basics on how to conduct a health preference study. After the mid-morning break, attendees will be broken into groups and asked to assess an example study as a hands-on exercise. Richard De Abreu Lourenço and Elisabeth Huynh will then review examples of challenges faced while assessing preferences in marginalised groups. The workshop builds directly from the textbook under development by IAHPR members and incorporates the experiences of scientists working with the region.

After lunch, the Academy will host a symposium on "Giving a voice to marginalised groups for health care reform." This symposium will be on the priorities of groups that are difficult to reach/neglected/outside of the mainstream in health policy. Specifically, it will focus on the preference evidence of four marginalised groups (adolescents and young adults [AYA]; lesbian, gay, bisexual, transgender, intersex and questioning [LGBTIQ]; members of indigenous populations; and persons with disabilities) and its implications for health care reform. In complement to advocacy and developing health policies that matter, having an understanding of their perspectives is an essential precursor to reforms that may better serve their social and health care needs. After the presentations by invited speakers, the panel will discuss key topics defined in advance by the co-chairs followed by a question and answer session. After the symposium, the Academy will host a networking dinner, including a brief welcome speech from the IAHPR Foundation, which is handling all meeting arrangements.

Starting at 8:00 on Tuesday, 3 December 2019, the Academy will host the scientific meeting including peer-reviewed podium presentations, lunch (with poster session), and a business session. The abstract submission system opened in April 2019 and closed on 25 September 2019.

### Disclaimer

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

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#### Patient Preferences for Approaches to Cancer Treatment: Trading Between Quality of Life and Survival

Alison Pearce<sup>1</sup>, Deborah Jane Street<sup>2</sup>, Deme Karikios<sup>3</sup>, Rosalie Viney<sup>2</sup>

<sup>1</sup>Sydney School of Public Health, University of Sydney, Australia; <sup>2</sup>Centre for Health Economics Research and Evaluation, University of Technology Sydney, Australia;

<sup>3</sup>Nepean Cancer Care Centre and Nepean Clinical School, University of Sydney, Australia

**Background:** Clinicians and patients with cancer are increasingly faced with making trade-offs between the (possibly small) benefits of treatment and potential side effects that reduce quality of life. Our research aimed to determine what and how people trade-off between quality of life and survival when choosing an approach to cancer treatment.

**Methods:** A discrete choice experiment (DCE) was conducted with an online panel sample of 300 adults with a previous diagnosis of cancer. Attributes included treatment duration and efficacy, side effect duration, and quality of life (based on the QLU-C10D, a cancer-specific utility instrument). Each participant completed 16 choice sets. We used mixed logit models to analyse preferences and heterogeneity of preferences for each attribute.

**Results:** The sample was older and reported poorer health than the general population. Melanoma, prostate and breast were the most commonly reported cancers. Additional survival was associated with a significant increase in the chance of a treatment being selected (p < 0.01), and most side effects needed to be severe to influence treatment selection. There was heterogeneity in all attributes, but nausea, pain, and reduced mobility were the side effects participants were most willing to trade survival to avoid (willing to trade 10, 11, and 16 weeks respectively).

**Conclusions:** People with cancer are reluctant to trade survival for quality of life, although the type and severity of side effects influences their choice. Heterogeneity of preferences highlights the importance of patient-centred decision making about approaches to and goals of cancer treatment.

#### Community Preferences for Care at the End of Life: The Final Three Weeks with Cancer

Deborah Jane Street<sup>1</sup>, Patricia Kenny<sup>1</sup>, Jane Hall<sup>1</sup>, Jane Phillips<sup>2</sup>, Meera Agar<sup>2</sup>

<sup>1</sup>Centre for Health Economics Research and Evaluation, University of Technology Sydney, Australia;

<sup>2</sup>Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT), University of Technology Sydney, Australia

**Background:** Demographic change in Australia and elsewhere means that more people than ever before are living to older ages and dying from progressive, life limiting conditions. Previous research finds that the majority of Australians prefer to die at home, although most die in hospital. This paper assesses the strength of preferences for end of life care, focusing on location of care and of death in the final 3 weeks of life for elderly cancer patients while including other contextual information.

Methods: A discrete choice experiment asked respondents to choose which of two care trajectories they considered to be better. By asking

about completed trajectories we avoid the need for the probabilistic information involved in a prospective decision and of having an opt-out option. We included 12 attributes and, both to make the task less demanding and to stop decisions that focused on only one attribute, we presented respondents with choice sets in which only about half of the attributes differed between the two options. We used an Australian population sample aged 45 or more from an online panel, with age-gender quotas to match the Australian population aged 45 or over. We used a mixed logit model to explore preference heterogeneity.

**Results:** Care that is predominately provided in hospital is the least favoured care option and although there is significant variability about the estimated mean, almost no respondents perceive it to be better than care that is predominantly provided at home. Care predominantly provided in a specialised palliative care unit was not significantly different from care that is predominantly provided at home. On average, the place of death is not important to respondents, although there is significant variability around death in hospital compared to at home. Overall, a greater emphasis was placed on pain control, cost and patient and carer well-being relative to location of care or death.

**Conclusions:** Using a DCE to give context about the death means that people can make a more informed decision about various aspects of care at the end of life. In particular, with the context information provided, people find that there are other aspects of care that are more important than dying at home.

### Exploring Heterogeneity in Moral Terminology Used by Patients in Palliative Care Consultations

Eline van den Broek-Altenburg<sup>1</sup>, Robert Gramling<sup>1</sup>, Kelly Gothard<sup>2</sup>, Maarten Kroesen<sup>3</sup>, Caspar Chorus<sup>3</sup>

<sup>1</sup>University of Vermont, College of Medicine, Burlington, USA; <sup>2</sup>University of Vermont, Department of Computer Science, Burlington, USA; <sup>3</sup>Delft University of Technology, Engineering Systems & Services

department, The Netherlands

**Background:** Optimizing end-of-life (EOL) care involves integrating decisions at various levels for patients and palliative care (PC) physicians. Measuring "quality" in PC delivery is therefore challenging and often not assessed. One focus of quality is to measure features of communication that help us understand patients' personal values and beliefs that influence choices fostering patient-centered treatment. These can be derived from the vocabulary patients use and we can use this knowledge to differentiate and respond more accurately to the needs of patients. The objective of this study was to specifically identify "moral" words that patients use in PC consultations and analyze if religion, self-reported EOL preferences, spiritual needs, uncertainty and emotional feelings are related to differences in moral lexicon of PC consultations.

**Methods:** We used text data from 240 audio-recorded and transcribed inpatient PC consultations and data from patient questionnaires at two large academic medical centers in the United States. We used the Moral Foundations Dictionary, an established list of moral words in the English language, to extract moral words from the text using Natural Language Processing. With a latent class analysis we explored if there were qualitatively different underlying patterns in the PC patient population. We used count models to analyze different types of morality in the conversations and explore if heterogeneous patterns of morality terms in patients exist.

**Results:** We found two latent classes: class one in which patients did not use many expressions of morality (about two thirds) in their PC

**Conclusions:** This study is among the first to use text data from a realworld situation to extract information regarding individual moral expressions and the relation with patient characteristics, attitudes and emotions. The results of this study are relevant to those who seek to improve the quality of communication in order to achieve better values-concordant treatment at EO

#### **References:**

Graham J, Haidt J, Koleva S, Motyl M, Iyer R, Wojcik SP, Ditto PH. Moral foundations theory: The pragmatic validity of moral pluralism. In Advances in experimental social psychology 2013 Jan 1 (Vol. 47, pp. 55–130). Academic Press.

#### Eliciting Quality Adjusted Life Years using the Time Trade Off Method for Prader–Willi syndrome

Tara A. Lavelle<sup>1</sup>, Norah L. Crossnohere<sup>2</sup>, John F. P. Bridges<sup>3</sup>

<sup>1</sup>Tufts University School of Medicine;

<sup>2</sup>Johns Hopkins Bloomberg School of Public Health;

<sup>3</sup>The Ohio State University Wexner Medical Center

**Background:** Prader–Willi syndrome (PWS) is a rare disease characterized by obesity and insatiable hunger (hyperphagia). There is no cure and it is unknown whether symptom improvement from potential treatments would improve quality-adjusted life years (QALYs) measured with direct elicitation methods. The goal of this study was to examine the acceptance and face validity of using a novel time trade off (TTO) method to value PWS health states, and derive QALYs for these health states.

**Methods:** We developed and fielded an online U.S. national survey to PWS caregivers. We asked caregivers to answer TTO questions to value three health states for a hypothetical 18-year-old with PWS: (1) Untreated PWS, (2) PWS without obesity, (3) PWS without obesity or hyperplasia. In novel TTO questions developed with input from PWS stakeholders, we asked whether it would be better for the hypothetical PWS individual to live 20 additional years in the health state described, or live fewer years completely healthy. We calculated QALYs from TTO values, excluding respondents without answers or with repetitive answers to all TTO questions. We used negative binomial regression analyses to examine how the health state symptoms influenced TTO amounts.

**Results:** Among 458 survey participants, 226 (49%) completed the TTO questions and met eligibility criteria (respondents). Characteristics of respondents were similar to non-respondents. Respondents valued untreated PWS at 0.69 QALYs, PWS with controlled obesity at 0.79 QALYs, and controlled hyperphagia/obesity at 0.92 QALYs. In adjusted analyses, PWS with controlled obesity, and controlled obesity and hyperphagia were associated with significantly higher health state values compared to untreated PWS (p < 0.01).

**Conclusions:** Despite low response rates, using these novel TTO methods to elicit QALYs for PWS demonstrated good face validity, and respondents were similar to non-respondents. PWS health states with controlled symptoms are associated with significantly higher QALYs compared to untreated PWS.

#### Valuing EQ-5D-5L: Comparing the Time Trade Off and Discrete Choice Experiment Valuation Methods

Brendan Mulhern<sup>1</sup>, Richard Norman<sup>2</sup>, Deborah Street<sup>1</sup>, Koonal Shah<sup>3</sup>, Emily Lancsar<sup>4</sup>, Julie Ratcliffe<sup>5</sup>, Rosalie Viney<sup>1</sup>

<sup>1</sup>University of Technology Sydney; <sup>2</sup>Curtin University; <sup>3</sup>PHMR London; <sup>4</sup>Australian National University; <sup>5</sup>Flinders University

**Background:** Two elicitation approaches used to develop EQ-5D-5L value sets are the Time Trade Off (TTO) and Discrete Choice Experiment (DCE). The recommended international valuation protocol (the EQ-VT) includes both TTO and DCE without duration. However, DCE with duration (DCETTO) has also been used. The methods may lead to differences in value set characteristics, and it is important to compare the values generated. The aim of this study was to compare the EQ-VT and an online DCETTO protocol.

**Methods:** Data were collected from 302 Australians. Sample A (n = 151) completed the EQ-VT followed by the DCETTO, and Sample B (n = 151) completed the DCETTO followed by the EQ-VT. The EQ-VT included 15 TTO and 14 DCE tasks, and the DCETTO included 15 tasks. Value sets were modelled using hybrid, conditional logit and preference heterogeneity models and the characteristics were compared. We also compared the DCETTO estimates to the actual TTO values. Self-reported acceptability questions were also assessed.

**Results:** The methods led to differences in the value sets produced. The DCETTO value set had a wider range than TTO (where the worst health state had values of -0.923 and -0.342 respectively). The relative magnitude of values for the mildest health states differed between approaches. Pain/discomfort and anxiety/depression consistently had the largest decrement, but the order of the other dimensions varied. For the 86 states included in the TTO, the actual TTO value differed from the estimated DCETTO value by between 0.003 and 0.622. Both the TTO and DCE were acceptable to respondents.

**Discussion:** This is the first study directly comparing three health state valuation methods using a within-person study design and accounting for potential ordering effects. Insights from the results will add to the evidence regarding similarities and differences between the methods. This will inform the future development of EQ-5D valuation protocols.

# Peruvian Valuation of the EQ-5D-5L: A Direct Comparison of cTTO and DCE

Federico Augustovski<sup>1</sup>, María Belizán<sup>1</sup>, Luz Gibbons<sup>1</sup>, Nora Reyes<sup>2</sup>, Elly Stolk<sup>3</sup>, Benjamin M Craig<sup>4</sup>, Romina A. Tejada<sup>1</sup>

<sup>1</sup>Institute for Clinical Effectiveness and Health Policy (IECS), Buenos Aires, Argentina;

<sup>2</sup>Unidad de Análisis y Generación de Evidencias en Salud Pública, Instituto Nacional de la Salud, Lima, Peru;

<sup>3</sup>EuroQol Research Foundation, Rotterdam, The Netherlands;

<sup>4</sup>University of South Florida, Tampa, Florida, USA

**Background:** Under the EuroQol Valuation Technology (EQVT) protocol, the composite time trade-off (cTTO) asks subjects to choose iteratively between health problems and reduced lifespan until indifferent, interpreted on a scale from 1 to -1 QALY. In its discrete-choice experiment (DCE), subjects choose simply between two outcomes (paired comparison). Objectives: Our aims were to (1) produce EQ-5D-5L values from the perspective of Peruvian general population; (2) demonstrate the feasibility of a "Lite" protocol that relies on fewer subjects, and (2) directly compare cTTO and DCE value sets.

**Methods:** A random sample of adults (N = 1000) was recruited in Lima, Arequipa and Iquitos for an interview survey. Some subjects (300) were randomly selected to first complete 11 cTTOs. All respondents were asked to complete 10 pairs with five EQ-5D-5L attributes and 12 matched pairs (A vs. B and B vs. C) with EQ-5D-5L and lifespan attributes. We estimated a cTTO heteroskedastic tobit (N = 300) model [1] and three DCE Zermelo-Bradley-Terry (ZBT) models (300, 700, and 1000) [2], each with the same 20 incremental parameters.

**Results:** Each model produced a suitable value set (i.e., 20 positive parameters); however, their lowest values differed greatly (cTTO: -1.076 [N = 300]; DCE: -0.984 [300]; 0.048 [700], -0.213 [1000]). Compared to the cTTO, the DCE (N = 300) produced different parameters (Pearson's correlation = 0.541), fewer insignificant parameters (0 vs 8) and fewer QALY values less than zero (26% vs 44%). The DCE values (n = 700) were higher, but similar (Pearson's correlation = 0.800).

**Conclusions:** Apart from an EQ-5D-5L value set for Peru, the results demonstrate that the "Lite" protocol was feasible and illustrate fundamental differences between cTTO and DCE values. Because the values disagree, both methods may not be valid. Do Peruvian adults prefer "immediate death" (DCE) over almost half of the EQ-5D-5L outcomes (cTTO) or just a handful of extreme problems (DCE)?

#### **References:**

1. Pickard AS, Law EH, Jiang R, Pullenayegum E, Shaw JW, Xie F, Oppe M, Boye KS, Chapman RH, Gong CL, Balch A, Busschbach JJV. United States Valuation of EQ-5D-5L Health States Using an International Protocol. Value Health. 2019 Aug;22(8): 931–941. doi: 10.1016/j.jval.2019.02.009. Epub 2019 May 25.

2. Craig BM, Rand K. Choice Defines QALYs: A US Valuation of the EQ-5D-5L. Med Care. 2018 Jun;56(6): 529–536. doi: 10.1097/ MLR.00000000000012.

### Does Combining Data from the Laboratory with a DCE Improve Our Understanding of Decision-Making?

Emily Lancsar<sup>1</sup>, Jemimah Ride<sup>2</sup>, Zack Dorner<sup>3</sup>

<sup>1</sup>Australian National University; <sup>2</sup>University of Melbourne; <sup>3</sup>University of Waikato

**Background:** There is growing interest in the possibilities offered by experimental economics to improve methods used in health economics. Here we study the application of methods from the experimental economics laboratory to health-related discrete choice experiments (DCEs). The hypothesis is that we can improve our understanding of participants' preferences by estimating novel, more comprehensive, preference models, now accounting for or making fewer assumptions about factors usually not captured in a DCE.

**Methods:** The setting for this study is a DCE examining preferences for programs designed to improve nutrition and/or physical activity. These lifestyle choices are highly relevant to the pervasive problem of obesity, and carry significant health impacts. The DCE examines preferences for type of program, cost, program goals, and financial incentives for achievement of weight loss goals. We use laboratory methods to measure respondents' time preferences, intrinsic motivation, and physical stature, incorporating each into the preference model. Using mixed logit estimation we compared a model with attributes and covariates to the same

model with the addition of the variables from the laboratory. We test whether harnessing additional variables from the laboratory has any significant effect on our estimates of preference by examining the impact on model coefficients and on willingness-to-pay for program attributes.

**Results and conclusions:** Measures of time preference and physical stature are statistically significant explanatory variables in our model. Adding these to the model did not change preferences in relation to the attributes of the nutrition and exercise programs nor other covariates, improved the statistical properties of the models (AIC and BIC) and impacted the estimated willingness-to-pay for program attributes. We discuss policy insights, implications for DCE practice and methodological questions raised by these findings.

### Whose Priorities Matter? Comparing Patient and Societal Preferences for Type 2 Diabetes Outcomes

Norah L Crossnohere<sup>1</sup>, Ellen M Janssen<sup>2</sup>, Sarah Janse<sup>3</sup>, John F. P. Bridges<sup>3</sup>

<sup>1</sup>Johns Hopkins Bloomberg School of Public Health; <sup>2</sup>Center for Medical Technology Policy; <sup>3</sup>The Ohio State University Wexner Medical Center

**Background:** There is a growing movement to consider patient priorities alongside societal values in healthcare decision making. We compared Likert-rating and best-worst scaling (BWS) methods for the prioritization of type 2 diabetes (T2D) treatment outcomes among patients and the general public.

**Methods:** Members of the American public and patients with T2D from a nationally representative panel participated in an online, cross-sectional survey. Participants evaluated seven T2D treatment outcomes (hypoglycemic events, A1c, weight loss, mental health, functioning, glycemic stability, and cardiovascular health) using a Likert-type scale (not important = 0, somewhat important = 5, very important = 10), and BWS case 1. Sample-stratified mean Likert-scores were calculated for outcomes, and BWS data were analyzed using mixed logistic regression (probability re-scaled to sum to 100). Respondents indicated whether each method was 'relevant to them' and 'easy to understand' (agree/disagree). Acceptability of each method was defined as  $\geq 75\%$  agreement with these items.

**Results:** 314 members of the public and 313 patients participated in the survey. Likert scores for attributes ranged from 7.1–9.1 across samples, while BWS prioritization weights ranged from 2.5–37.5. Both samples rated glycemic stability, cardiovascular health, and A1c among the three outcomes in both Likert-rating and BWS. In Likert, patients more highly rated A1c than the public (9.1 vs 7.9, P < 0.001). In BWS, patients more highly valued A1c (37.5 vs 21.4, P < 0.001), and functioning (4.8 vs 7.6, P = 0.04) than the public. Patients met/exceeded 75% acceptability benchmarks for both methods, however the public meet benchmarks for neither method.

**Conclusions:** That the public did not find either prioritization method relevant or understandable demonstrates the importance of including patients' priorities in healthcare decision making. BWS better distinguished between the relative importance of attributes in this study, but is generally considered more burdensome to respondents. It is therefore significant to preference researchers that patients found the more complex BWS approach acceptable even after completing the simple Likert rating task.

#### Eliciting Relative Importance of Subjective Wellbeing Dimensions: Empirical Comparisons of 4 Methods

Gang Chen<sup>1</sup>, Angelo Iezzi<sup>1</sup>, Jeff Richardson<sup>1</sup>

#### <sup>1</sup>Monash University

**Background:** To understand the relative importance of different dimensions of a subjective wellbeing (SWB) instrument, and to explore the comparability of findings from different approaches.

Methods: The study focused on the five-item World Health Organization Wellbeing Index (WHO-5). Four different methods were used in this study. (1) Rating tasks, in which respondents were asked to directly rate the importance of each SWB dimensions. (2) A profile case best-worst scaling (BWS) method. By which, respondents were requested to indicate the best and worst features of a series of SWB profiles derived from the WHO-5 descriptive system. The BWS data were then analysed based on random utility theory. (3) The experience-based method, i.e. the relative importance was derived by regressing the overall life satisfaction on different SWB dimensions. (4) Data mining technique. In particular, a multilayer perceptron feedforward artificial neural network technique was adopted. An online survey was developed for the administration in Australia, whilst respondents were recruited through an online panel company. Results: A sample of 900 Australian adult respondents (51% female; mean age: 45 years old, range 18-79 years old) were analysed. Relative importance elicited based on four methods are not identical. Most methods found that 'felt cheerful and in good spirits' and 'felt calm and relaxed' are two most important dimensions, whilst there was not a clear conclusion on the other three dimensions, 'woke up feeling fresh and rested', 'daily life has been filled with things that interest me', and 'felt active and vigorous'. Potential reasons for the inconsistent rankings from different methods were discussed.

**Conclusions:** This study demonstrated that depends on the methods been applied, the elicited relative importance varied. The outputs of this study also enriched our understanding of the association between population's characteristics and relative importance on different dimensions of an SWB measure.

### Patient Preferences for Provider Choice: A Discrete Choice Experiment

Eline van den Broek-Altenburg<sup>1</sup>, Adam Atherly<sup>1</sup>

#### <sup>1</sup>University of Vermont, College of Medicine, Burlington, USA

**Background:** Narrow network insurance plans, restricting provider choice, are popular among patients buying health insurance in the United States. However, it is unknown what aspects of provider choice matter the most to them. This study uses a discrete choice experiment to estimate a model of patient preferences regarding attribute(s) of the network of primary care providers and willingness to pay for open networks in health insurance plans.

**Methods:** Data were collected from an online survey in December 2017. Respondents were asked to complete 12 choice tasks differing in the levels of the attributes of the provider network. Attributes included wait time to see a primary care provider (in days), "breadth" of network (percentage of primary care providers accepting the plan), travel time to the nearest primary care provider (in minutes), whether the respondent's personal doctor is included and monthly premium. The levels were defined based on the literature and focus groups with patients in three different U.S. locations. We used mixed logit models to estimate preference-based utilities for attributes of primary care provider networks and willingness to pay.

Results: A nationally representative sample of 992 adults completed the survey. Coverage of a personal doctor was the most important attribute  $(\beta = 0.8105, p < .001)$ , followed by premium  $(\beta = -0.0085, p < .001)$ . Although wait time to see a primary care provider ( $\beta = -0.1315$ , p < .001), the breadth of the network ( $\beta = 0.0206$ , p < .001) and travel time to the closest doctor covered by the plan ( $\beta = -0.0045$ , p < .001) were statistically significant, the magnitude of the effect was smaller. On average, respondents were willing to pay \$94.86 more to get an insurance plan that covers care for their personal primary care doctor, and \$2.40 more for a plan with a broader network, controlling for coverage of the personal primary care doctor. We also estimated the attribute weights in terms of wait time: respondents were willing to wait 6 days more to see a primary care doctor to have a plan that covers care with their personal doctor. Some of the systematic differences could be explained by individual characteristics, such as health status, gender and income. The results were robust to various specifications, including a mixed logit model allowing correlated random coefficients.

**Conclusions:** This study provides new insights to efforts to develop new models or standards on provider network adequacy and access to care.

### Does the Price Premium for Branded Medicines Reflect Preferences? A Case Study from Australia

Elena Meshcheriakova<sup>1</sup>, Stephen Goodall<sup>1</sup>, Deborah Jane Street<sup>1</sup>, Rosalie Viney<sup>1</sup>

<sup>1</sup>Centre for Health Economics Research and Evaluation, University of Technology Sydney, Australia

**Background:** Being the first prescription medicine to market provides an advantage that persists even after patent expiry allows competition from generics: brand becomes associated with the treatment and confers value. Whether this arises from a doctor's prescribing practice, familiarity, advertisements, or word of mouth is difficult to disentangle. In Australia, medicines are subsidised but manufacturers can charge the consumer a brand premium (an amount above the fixed co-payment) for the branded medicine. Despite higher prices for essentially the same product utilisation of the medicine with a brand premium persists. We evaluated consumer preferences for medicines with and without a brand premium.

Methods: We designed a DCE in which consumers were asked to choose their preferred prescribed medicine - branded or generic - for a hypothetical health condition. The DCE included a binary context attribute reflecting whether the doctor wrote a brand name or the compound name on the script. The attributes of each prescribed medicine included the product name, cost, brand premium, collection time and pharmacist's recommendation. There were three arms providing different information about cost. Arm 1: cost was described by one attribute representing the out of pocket cost to the consumer; arm 2: cost was described by an attribute representing price to the consumer and an additional binary attribute indicating whether the price included a brand premium; arm 3: cost was described by an attribute representing the price to the consumer and an additional attribute indicating the amount that a brand premium contributed to that price (zero if there is no brand premium). Respondents saw 6 examples of each script type. Respondents were recruited via an on-line panel. Analysis was undertaken with mixed-logit and latent class models. Results: 1203 respondents, randomly allocated to the three arms, completed the study. Consumers prefer branded medicine to other products at lower prices but are indifferent to product type at higher prices. In arm 2

consumers were willing to pay up to a \$1 more for a product with a brand premium but in arm 3 respondents showed an unwillingness to pay for a product that included a brand premium.

**Conclusions:** When generic competition is available, pharmaceutical prices should fall, however, this experiment shows that brand premiums may inadvertently distort the market for pharmaceuticals.

### Pharmacist Preferences for Prescribing Models in primary Care in NZ: A Discrete Choice Experiment

Rakhee Raghunandan<sup>1</sup>, Carlo A Marra<sup>1</sup>, June Tordoff<sup>1</sup>, Alesha Smith<sup>1</sup>

<sup>1</sup>School of Pharmacy, University of Otago, Dunedin, New Zealand

**Background:** The non-medical prescribing workforce in New Zealand (NZ) is evolving as more health professionals gain prescribing rights. Given the slow uptake of prescribing by pharmacists, a discrete choice experiment was used to understand which prescribing models practising community pharmacists would prefer in primary care.

**Methods:** The stated choice survey included attributes developed from the literature and refined following qualitative feedback from pharmacists. The four attributes were location of prescribing service, education requirement for prescribing, professional service fee charge, and change in

pharmacist's income. The labelled alternatives were five different prescribing models proposed for community pharmacists: independent prescribing, collaborative prescribing, delegated prescribing, minor ailments prescribing, and 'pharmacist only medicines' prescribing. An availability design was required to show three out of the five labelled alternatives in each choice task. A D-efficient design was obtained using Ngene design software and Excel, with 30 choice tasks in three blocks of 10 choice tasks each. The survey was distributed online and analyses included multinomial logit and random parameters logit models.

**Results:** 264 practising community pharmacists fully completed the online survey, resulting in 2640 observations. Random parameter logit model estimation indicated stronger preferences for the minor ailments and collaborative prescribing models, compared to the 'pharmacist only medicines' prescribing model (p < 0.05). Random parameter logit analysis suggested evidence of preference heterogeneity for these prescribing models (p < 0.01). A pharmacist prescribing service located at the community pharmacy was preferred compared to at a GP practice (p < 0.001). The accredited learning modules option i.e. micro credentialing was the strongest education requirement preference (p < 0.01).

**Conclusions:** This is the first discrete choice experiment used in pharmacy in NZ to explore community pharmacist preferences for prescribing models in primary care. The study offers insight into community pharmacist preferences and has the potential to be used when developing sustainable and well-utilised pharmacist prescribing services and education.



### **BUSINESS SESSION**

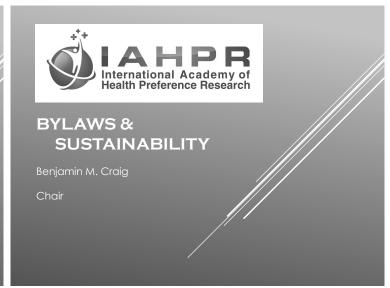
Opening, Richard De Abreu Lourenço, Meeting Co-Chair Bylaws and Sustainability, Benjamin M. Craig, Chair Publications, Emily Lancsar, Director of Outreach *The Patient*, Christopher Carswell, Editor in Chief Meetings, Elisabeth Huynh, Meeting Co-Chair Closing, Richard De Abreu Lourenço, Meeting Co-Chair

### **OVERVIEW**



## **OPENING**

Meeting Co-Chair



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

Foundation Board

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







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Region 1 (UTC -1 to +3) Esther W. de Bekker-Grob (2020-2025) Axel C. Mühlbacher (2015-2022)

Region 2 (UTC +4 to +12) Emily Lancsar (2016-2020 or 2023) (Election in 2020)

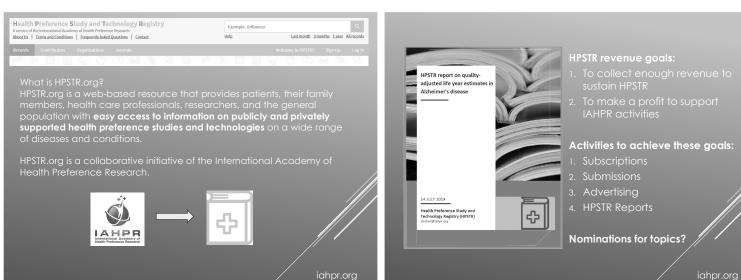
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- Tenured members:
   Pay for at least one event per year,
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   Invited, but not required to vote, review abstracts, chair meetings, and lead other IAHPR activities.

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





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## PUBLICATIONS

Emily Lancsa

Director of Outreach

Stage-3 Compliation (Drafted) hapter 1 Introduction hapter 2 (dentification and description of hapter 3 Preference-elicitation (Jask hapter 4 Choice task construction hapter 5 Experimental design hapter 5 Aurvey instrument hapter 7 Data collection hapter 8 Interpretation and presentation

Recently Approved Chapters (Under Developmen Chapter 10 Applications Chapter 11 Relevance Chapter 12 Advanced Topics

Our book bas 51 authors inclu

Our book has 51 authors, including 36 tenured and 13 regular members and 2 non-members.

### METHOD FOR HEALTH PREFERENCE RESEARCH



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Stage 4 (Reviewing; mid-July to late August) has three objectives:
(1) Solicit comments on the chapters from targeted IAHPR members.
(2) Prepare revised and robust outlines for the remaining content of the book
(3) Amend the chapters as needed. CrossMark Patient DOI 10.1007/s40271-017-0253-9 COMMENTARY Stage 5 (Harmonizing; September to late November) has two objectives: (1) Harmonize the first nine chapters (i.e. D. Brown sabbatical) (2) Draft the remaining content Health Preference Research: An Overview Benjamin M. Craig $^1\cdot$  Emily Lancsar $^2\cdot$  Axel C. Mühlbacher $^3\cdot$  Derek S. Brown $^4\cdot$  Jan Ostermann $^5$ Stage 6 (Refinement; December to February) has two objectives:(1) Refine the first nine chapters(2) Change requests for the remaining content © Springer International Publishing Switzerland 2017 METHOD FOR HEALTH Health preference research (HPR) is dedicated to underdistinct preferences within groups (market segmentation). preference estimates and segmentation results may be incorporated into cost-effectiveness analyses (CEAs), or shared deci-nutli-criteria decision analyses (MCDAs), or shared deci-sion making (SDM). This overview provides a brief PREFERENCE RESEARCH standing the value of health and health-related goods and services. The mantra in HPR is "Choice defines value". With a better understanding of what patients want, provi-ders, regulators, and policy makers can better meet the iahpr.org



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

COMMENTARY

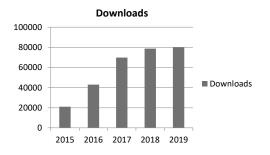
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### **Journal Headline Metrics**

- Over 400 Submissions
- 78, 418 downloads in 2018
- Impact Factor 2.67
- Submission to first decision: 21 days
- Acceptance to publication: 17 days

### Usage



### Usage

Top 10 Full-Text Article Requests 2019 to date

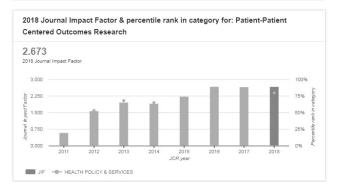
Title	Authors	Year	Download s
Sample Size Requirements for Discrete Choice Experiments	Bekker et al.	2015	3,223
Patient-Community perspectives on real-world evidence	Oehrlein et al.	2019	1,794
Measuring Patient Experience	Ahmed et al.	2014	1,612
Tools measuring quality of death, dying and care after death	Kupeli et al	2019	1,421
Oh, the places we'll go: PRO's and electronic health records	Wu et al.	2018	1,267
PRO's in atopic dermatitis	Barrett et al.	2019	1,197
Patient reported symptoms over 48 weeks among participants in phase III trials of Adults with HIV receiving co-formulated bictegravir, emtricitabine, and tenofovir alafenamide	Martin et al.	2018	1,176
Patient preferences in the medical product life cycle: what do stakeholders think?	Janssens et al.	2019	1,150
Treatment decisions for advanced non-squamous non-small cell lung cancer	Muller et al.	2019	1,125
A patient-centered description of severe asthma	Winders et al.	2019	1,082

### Impact Factor

InCites Journal Citation Reports

Clarivate

Page 1 of 1





tted Manuscripts (2018)

or Country of Origin of Sub

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### Impact Factor

Top ranking highest cited 2017-2018 articles for IF Year 2019

Title	Author	Total Citations*	Citations for IF 2017			
A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay	Gordon, Louisa G.; Merollini, Katharina M. D.; Lowe, Anthony; Chan, Raymond J.	39	21			
Giving Patients' Preferences a Voice in Medical Treatment Life Cycle: The PREFER Public-Private Project	de Bekker-Grob, Esther W et al.	26	16			
Patient Preferences for Oral Anticoagulation Therapy in Atrial Fibrillation: A Systematic Literature Review	Wilke, Thomas; Bauer, Sabine; Mueller, Sabrina; Kohlmann, Thomas; Bauersachs, Rupert	23	10			
A Systematic Review and Meta-Synthesis of Patients' Experiences and Perceptions of Seeking and Using Benzodiazepines and Z-Drugs: Towards Safer Prescribing	Sirdifield, Coral; Chipchase, Susan Y.; Owen, Sara; Siriwardena, Aloysius Niroshan	13	6			
Assessing the Use of a Feedback Module to Model EQ- 5D-5L Health States Values in Hong Kong	Wong, Eliza L. Y.; Ramos-Goni, Juan Manuel; Cheung, Annie W. L.; Wong, Amy Y. K.; Rivero-Arias, Oliver	13	5			
Patients' Preferences for Outcome, Process and Cost Attributes in Cancer Treatment: A Systematic Review of Discrete Choice Experiments	Bien, Daniela R.; Danner, Marion; Vennedey, Vera; Civello, Daniele; Evers, Silvia M.; Hiligsmann, Mickael	11	8			

### Altmetric Top 5

Scor e	Article DOI	Title	Author(s)	Publication Date
67	10.1007/s40271-017- 0270-8	Evaluation of Patient and Family Engagement Strategies to Improve Medication Safety	JULIA M. KIM, CATALINA SUAREZ- CUERVO, ZACKARY BERGER, JOY LEE, JESSICA GAYLEARD, CAROL ROSENBERG, NATALIA NAGY, KRISTINA WEEKS, SYDNEY DY	09-08-2017
67	10.1007/s40271-012- 0001-0	Social Stigma in Diabetes : A Framework to Understand a Growing Problem for an Increasing Epidemic.	JASMIN SCHABERT, JESSICA L. BROWNE, KYLIE MOSELY, JANE SPEIGHT	16-01-2013
62	10.1007/s40271-014- 0065-0	A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities	JO BRETT, SOPHIE STANISZEWSKA, CAROLE MOCKFORD, SANDRA HERRON-MARX, JOHN HUGHES, COLIN TYSALL, RASHIDA SULEMAN	18-07-2014
44	10.1007/s40271-017- 0215-2	Seeing is Engaging: Vlogs as a Tool for Patient Engagement	JOY L. LEE, MARY FREY, PETER FREY, ILENE L. HOLLIN, ALBERT W. WU	18-01-2017
39	10.1007/s40271-016- 0206-8	Patient and Public Involvement in the Development of Healthcare Guidance: An Overview of Current Methods and Future Challenges	AHMED RASHID, VICTORIA THOMAS, TONI SHAW, GILLIAN LENG	09-11-2016

How is the Altmetric score calculated? The score is a weighted count

The score is a weighted count of the different sources (newspaper stories, tweets, blog posts, comments) that mention the paper.

Why is it weighted? To reflect the relative importance of each type of source. It's easy to imagine that the average newspaper story is more likely to bring attention to the paper than the average tweet. This is reflected in the default weightings.

## Author Satisfaction



### **Future Plans**

- Look to explore further themed issues and **Topical Collections**
- Appoint some patient advocates to the editorial board
- Ongoing collaboration with IAHPR
- · Prioritise good quality reviews/tutorials of methods for publication
- Encourage IAHPR members to submit their best work to the journal

### Summary

- · Continue to receive a high level of submissions (approx 400 estimated for 2019)
- Usage continues to increase
- Citations are steady
- Successful first year of our association with IAHPR

# O. Aiyegbusi University of Birmingham, Birmingham, England Z. Berger, John Hopkins School of Medicine, Baltimore, MD, USA

K. Beusterien, ORS Health, Washington, DC,

- USA John F.-P. Bridges, The Ohio State University, Columbus, OH, USA D.S. Brown, Washington University in St. Louis, St. Louis, MO, USA
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- C. Cunningham, McMaster University, Hamilton, ON, Canada
  E.W. de Bekker-Grob, Erasmus University Rotterdam, Rotterdam, the Netherlands

- L.W. de Bekker-Groß, Frasmus University Rotterdam, Rotterdam, the Netherlands K. Deal, McMaster University, Hamilton, ON, Canada J.G. Dolan, University of Rochester, Rochester, NY, USA K. Facer, University of Glasgow, Glasgow, Scotland S. Gener, University, of Glasgow, Glasgow, Scotland S. Research, Sydney, NSW, Australia Research, Sydney, NSW, Australia E. Fraenker, Jale University, New Haven, CT, HSA.

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### **MEETINGS**

Co-Chair



- Starting in 2020:
   Annual, instead of two per year
   Cycle across 3 regions: (UTC -1 to +3), (UTC +4 to +12), (UTC -11 to -2)
   Extend the meeting length, adding a half day.
   Hosted by the regional directors, not the IAHPR Office





making" Mentoring Dinner (16 Oct); Networking Dinner (Davanti Enoteca, 17 Oct)

Abstract Deadline: 3 August 2020

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13th IAHPR Meeting (2021) chaired by Michał Jakubczyk and Jorien Veldwijk TBD, Europe

14th IAHPR Meeting (2022) chaired by Gang Chen and Julie Ratcliffe Adelaide, South Australia, Australia (tentative)

15th IAHPR Meeting (2023) chaired by Christine Kistler and Deborah Marshall Philadelphia, Pennsylvania, USA (tentative)

### FUTURE MEETINGS

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### **CLOSING**

Richard De Abreu Lourenço Meeting Co-Chair

# Attendees

### IAHPR Members

- John F P Bridges, PhD, The Ohio State University College of Medicine
- Christopher Carswell, BSc, MSc, SpringerNature
- Gang Chen, PhD, Monash University
- Benjamin M. Craig, PhD, University of South Florida, Tampa, Florida, USA
- Richard De Abreu Lourenco, PhD, CHERE, UTS
- Kirsten Howard, PhD, School of Public Health, University of Sydney



- Elisabeth Huynh, PhD, Australian National University
- Emily Lancsar, PhD, ANU
- Brendan Mulhern, MRes, Centre for Health Economics Research and Evaluation, University of Technology Sydney
- Jason Ong, PhD, MMed, MBBS, FAChSHM, FRACGP, Monash University, London School of Hygiene and Tropical Medicine
- Alison Pearce, PhD, University of Sydney
- Julie Ratcliffe, PhD, Flinders University
- Deborah J. Street, PhD, University of Technology Sydney
- Rosalie Viney, PhD Economics, University of Sydney, Centre for Health Economics Research and Evaluation, University of Technology Sydney

### Non-Members

- Whenayon Simeon Ajisegiri, MBBS; MIPH; MHM; MPH, The George Institute for Global Health, Faculty of Medicine, University of New South Wales, Australia
- Adam J. Atherly, PhD, University of Vermont, Burlington, VT USA
- Mina Bahrampour, BSc, MSc, PhD candidate, Griffith University, Centre for Applied Health Economics
- Amy Louise Brown, MAppSc(Research), Townsville Hospital and Health Service, Townsville, Queensland, Australia;
- Margie Campbell, PhD, CHERE
- Nancy Joy Devlin, BA Hons; PhD, University of Melbourne, Australia & Office of Health Economics, London, UK.

Zack Dorner, PhD, University of Waikato

- Kim Edmunds, BA; MSCD; PhD candidate (health economics), Centre for Applied Health Economics; Menzies Health Institute Queensland, Griffith University
- Belinda Ford, MPH/ MHM, The George Institute for Global Health, UNSW Sydney

Sarah A. Janse, PhD, The Ohio State University Wexner Medical Center

My-Linh Nguyen Luong, MSPH, Centre for Health, Exercise and Sports Medicine

Elena Meshcheriakova, PhD Candidate, CHERE

Rakhee Raghunandan, BPharm, University of Otago, Dunedin, New Zealand

Jemimah R Ride, MBBS MPH PhD, University of Melbourne

Trudy Sullivan, PhD, University of Otago, Dunedin, New Zealand

Eline van den Broek-Altenburg, Ph.D, MS, MA, University of Vermont

Jo Watson, B.Soc.Sci, Pharmaceutical Benefits Advisory Committee, Australia

Caroline Watts, PhD, Kirby Institute

Esther Willing, PhD, University of Otago

Ross Wilson, PhD, University of Otago, Dunedin, New Zealand

Tim Wrightson, BSc, PGDipSci, Adis Journals

Jackie Yim, Ba. Applied Science, Centre for Health Economics Research and Evaluation

Alice Yu, PhD in Health Economics (in progress), Centre for Health Economics Research and Evaluation (CHERE), University of Technology Sydney (UTS)



### About Us

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

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

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