Broadening the Measurement and Valuation of Health and Quality of Life

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CERTIFICATE OF ORIGINAL AUTHORSHIP

I, BRENDAN MULHERN declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Business at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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THESIS FORMAT

This is a conventional thesis including seven chapters of content, references and further appendices. Two of the chapters (a literature review and empirical study) three empirical studies have resulted in published journal articles as described below.

PUBLISHED PAPERS RESULTING FROM THIS THESIS

1. **Mulhern B**, Norman R, DeAbreu Lourenco R, Street D, Malley J, Viney R. Investigating the relative value of health and social care related quality of life using a Discrete Choice Experiment. Social Science and Medicine. 2019; 233: 28-37.

   Author contribution for this paper: Brendan Mulhern led the conceptualisation of the study, developed the study design, constructed the experiment, and led the data analysis and interpretation and paper writing. Richard Norman, Richard De Abreu Lourenco, Deborah Street, Juliette Malley and Rosalie Viney supported the conceptualisation of the study and the development of the study design. They also contributed to the interpretation of the results and supported the development of the manuscript.

2. **Mulhern B**, Norman R, Street D, Viney R. One method, many methodological choices: A structured review of Discrete Choice Experiments for health state valuation. Pharmacoeconomics. 2019; 37(1):29-43.

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TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ABSTRACT

Economic evaluation is an important tool in health care resource allocation. Interventions are typically evaluated through a cost utility analysis (CUA) using the Quality Adjusted Life Year (QALY), a metric combining length of life and quality of life (QoL) into a single outcome. The quality aspect of the QALY is often provided by a preference-based measure (PBM) that includes a way of measuring health, and a preference-based value set. The most commonly used PBMs focus on health-related quality of life (HRQoL). However, there is a case for broadening what is measured and valued by including other aspects of QoL (such as social care related QoL) alongside HRQoL.

This thesis explores how methods for the measurement and valuation of health and QoL can be extended to inform the development of broader and more widely applicable instruments. This was investigated by first exploring how to incorporate QoL concepts into PBMs, and second by testing the further application of Discrete Choice Experiment (DCE) methods to value QoL. Three empirical studies were conducted

The first study assessed existing measures of health and QoL using Item Response Theory (IRT), and tested two ways in which PBMs could be broadened to incorporate wider QoL concepts. The results demonstrated overlap and divergence in what is measured. This informed where extra dimensions of QoL could broaden the information collected, and how the information collected within existing HRQoL frameworks could be extended.

The second study used DCE to understand respondent preferences for diverse dimensions of QoL. The results provided evidence respondents do trade across different concepts of QoL. This supports the need for broader measures, and also the use of DCE to value broader outcomes.

The third study focuses on DCE methods, and particularly on the construction of designs for DCEs. The results provided detailed information about different design strategies for the valuation of QoL outcomes.

The overall findings raise key issues about what should be captured in PBMs, and also provide novel information about methods that can be used to inform the assessment, development and valuation of future instruments. For example, the results inform how IRT can be used in PBM

development. They also suggest how DCE can be used to value diverse QoL concepts. This can inform the development and valuation of broader measurement systems of QoL outcomes that can increase the scope and enhance the applicability of QALY values used in resource allocation decision making.

LIST OF ABBREVIATIONS

Abbreviation	Description
15D	15 Dimension
A	Anxiety (PROMIS dimension)
ABC	Assessment of Burden of COPD
AC	Accommodation (ASCOT dimension)
AD	Anxiety/Depression (EQ-5D dimension)
AIC	Akaike Information Criterion
ANOVA	Analysis of Variance
AQoL	Assessment of Quality of Life
AQoL-8D	Assessment of Quality of Life – 8 Dimension
ASCOT	Adult Social Care Outcomes Toolkit
BIC	Bayesian Information Criterion
BPI	Behaviour Problems Index
BWS	Best Worst Scaling
CAT	Computer Adaptive Testing
CBA	Cost Benefit Analysis
CF	Crawford Ferguson
CFA	Confirmatory Factor Analysis
CL	Cleanliness (ASCOT dimension)
CO	Control (ASCOT dimension)
COPD	Chronic Obstructive Pulmonary Disease
CREATE	Checklist for Reporting Valuation Studies
CTT	Classical Test Theory
CUA	Cost Utility Analysis
D	Depression (PROMIS dimension)
DCE	Discrete Choice Experiment
DCE_{TTO}	Discrete Choice Experiment including duration
DEMQOL	Dementia Quality of Life
DI	Dignity (ASCOT dimension)
DIF	Differential Item Functioning
EFA	Exploratory Factor Analysis
EORTC	European Organisation for Research and Treatment of Cancer
EQALY	Extended Quality Adjusted Life Year
FA	Fatigue (PROMIS dimension)
FD	Food and Drink (ASCOT dimension)
GDP	Gross Domestic Product
GH	General health (SF-36 dimension)
GMNL	Generalised Multinomial Logit model
HRQoL	Health-Related Quality of Life
HTA	Health Technology Assessment
HUI-2	Health Utility Index – Mark 2
HUI-3	Health Utility Index – Mark 3
ICECAP	ICEpop CAPability measure for Adults
ICER	Incremental Cost Effectiveness Ratio
IIA	Independence of Irrelevant Alternatives
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
IRT	Item Response Theory

LL	Log-Likelihood
LLR	Log-Likelihood Restricted
LLU	Log-Likelihood Unrestricted
LR	Likelihood Ratio
LT-TTO	Lead Time – Time Trade-Off
MAUI	Multi-Attribute Utility Instrument
MH	Mental Health (SF-36 and SF-6D dimension)
MH-RM	Metropolis–Hastings Robbins-Munro algorithm
MIC	Multi Instrument Comparison
MNL	Multinomial Logit
MO	Mobility (EQ-5D dimension)
NICE	National Institute for Health and Care Excellence
OC	Occupation (ASCOT dimension)
ONS-4	Office of National Statistics – 4
OPUS	Older Person's Utility Scale
PA	Pain (SF-36, SF-6D and PROMIS dimension)
PBAC	Pharmaceutical Benefits Advisory Committee
PBM	Preference-Based Measure
PD	Pain/Discomfort (EQ-5D dimension)
PF	Physical Functioning (SF-36, SF-6D and PROMIS dimension)
PICOS	Participants, interventions, comparisons, outcomes, and study
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMIS	Patient-Reported Outcome Measure Information System
PWI	Personal Wellbeing Index
QALY	Quality Adjusted Life Year
QoL	Quality of Life
RE	Role Emotional (SF-36 dimension)
RF	Role Functioning (SF-6D dimension)
RMSE	Root Mean Squared Error
RMSEA	Root Mean Squared Error of Approximation
RP	Role Physical (SF-36 dimension)
RUT	Random Utility Theory
SA	Safety (ASCOT dimension)
SAS	Statistical Analysis Software
SC	Self-Care (EQ-5D dimension)
SCRQoL	Social Care Related Quality of Life
SD	Standard Deviation
SF-6D	Short Form – 6 Dimension
SF-36	Short Form – 36
SF	Social Functioning (SF-36, SF-6D and PROMIS dimension)
SG	Standard Gamble
SL	Sleep (PROMIS dimension)
SP	Social Participation (ASCOT dimension)
SWLS	Satisfaction With Life Scale
TIF	Total Information Function
TTO	Time Trade-Off
UA	Usual Activities (EQ-5D dimension)
VAS	Visual Analogue Scale

VNM	Von Neumann and Morgenstern
VT	Vitality (SF-36 and SF-6D dimension)
WEMWBS	Warwick and Edinburgh Mental Wellbeing Scale
WHO	World Health Organisation