2025 Directory of EuroQol PhD Network Members

Version 4.0 – 1 January 2025

Jia Jia Lee, Stevanus Pangestu, Ademola Joshua Itiola, Jan Faller, Ava Fee Helena Hoogenboom

Introduction

- EuroQol PhD Network was established in September 2022 for and by doctoral students conducting research on the measurement and valuation of health. The aim of the Network is to bring these students together and to offer a programme of activities to support their career development.
- The EuroQol PhD Network requires students to be actively enrolled in a doctoral program and conduct research aligned with the EuroQol scientific aims. A doctoral student must complete a brief application confirming the above-mentioned criteria, which is reviewed by the leadership of the Network (Joshua M. Bonsel, Benjamin M. Craig, Jia Jia Lee) and by the members of the Education and Outreach Working Group (EOWG) of the EuroQol Research Foundation.
- In September 2022, 21 students volunteered to be the founding members of the EQ PhD Network (see website). Since then, 12 members (Suzana Karim, Andrea Libório Monteiro, Maja Kuharic, Paul Schneider, Caique de Melo do Espirito Santo, Clement Cheuk Wai Ng, Anja Bischof, Xin Zhang, Haode Wang, Ling Jie Cheng, Aiping Chua, Rachel O'Loughlin) graduated, one member left their doctoral program. At present, the Network has a total of 45 active members.

EQ PhD Network Membership

To promote social cohesion and networking, the 45 Network members have provided a brief description of themselves and their research (1 page each, structured format). In this directory, the members are listed by seniority, starting with the founding members followed by those who joined more recently. Some students have presented at EuroQol meetings, published articles on EuroQol instruments, or received grants from the Foundation. The founding and newer members used slightly different forms, but the general structure is similar. For reference, the Appendix is the Code of Conduct for the 2024 EQ PhD Network members.

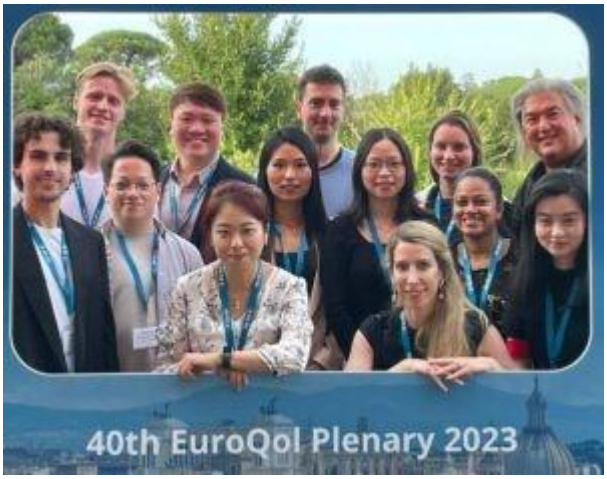
Using this directory, we hope to showcase the qualities and diversity of the 2025 cohort. Please feel free to contact its members directly. You may also send queries to its leadership via email (phdnetwork@euroqol.org).

EUROQOL PHD NETWORK RECEPTION AT THE 39TH EUROQOL PLENARY MEETING, CHICAGO, USA, 20 SEPTEMBER 2022

Photo taken by Dominik Golicki. (Left to Right): Meixia Liao, Rachel Lee-Yin Tan, Maja Kuharic, Ai-Ping Chua, Ling Jie Cheng, Xin Zhang, Suzana Karim, Jiajun Yan, Renee Jones, Yiting Luo, Diana Khanna, Maksat Jumamyradov, Benjamin M. Craig (previous co-chair). Doctoral students who attended the meeting but are not shown above include Giselle Aqwe Abangma, Andrea Libório Monteiro, and Jonathan Nazari.

EUROQOL PHD NETWORK RECEPTION HOSTED AT THE 7TH EUROQOL ACADEMY MEETING, MILAN, ITALY, 7 MARCH 2023

Photo taken by Nathalie Pangalos Bastaricca (Left to Right): Jonathan Nazari, Maja Kuharic, Paul Schneider, Guangjie Zhang, Yifan Ding, Haode Wang, Alexander van Heusden, Lilla Roy, Jia Jia Lee, Jiabi Wen, Rachel Lee-Yin Tan, Joshua Michael Bonsel (previous co-chair), Cheuk Wai Ng, Wenjing Zhou, Ling Jie Cheng, Zhongyu Lang, and Benjamin M. Craig (previous co-chair)



EUROQOL PHD NETWORK RECEPTION AT THE 40TH EUROQOL PLENARY 2023, ROME, ITALY, 19 SEPTEMBER 2023

Photo taken by Nathalie Pangalos Bastaricca (Left to Right): Jonathan Nazari, Joshua M. Bonsel (previous co-chair), Alexander van Heusden, Ling Jie Cheng, Wenjing Zhou, Guangjie Zhang, Paul Schneider, Meixia Liao, Maja Kuharic, Anja Bischof, Ashwini De Silva, Yiting Luo, and Benjamin M. Craig (previous co-chair)

EuroQol PHD Network Reception at the 8th EuroQol Academy, Copenhagen, Denmark, 5 March 2024

Photo taken by Nathalie Pangalos Bastarrica (Left to Right): Neo (Hsuanyun) Su, Marius Torjusen, Abraham Gebregziabiher Welie, Zhongyu Lang*, Anh Vu Nu, Ava Fee Helena Hoogenboom*, Rachel Lee-Yin Tan*, Abeer Al Rabayah*, Haode Wang*, Aiping Chua*, Joshua Michael Bonsel* (previous co-chair), Guangjie Zhang*, Yifan Ding*, Ling Jie Cheng*, Ivan Chi Ho Au, Stevanus Pangestu*, Thao Thai, Meixia Liao*, Ashwini Priyangika De Silva*, Jan Heijdra Suasnabar, Jonathan Nazari* and Benjamin M. Craig (previous co-chair).*

**Active Network members*

EuroQol PhD Network Members at the 41st EuroQol Plenary, Noordwijk, The Netherlands, 17 September 2024

Photo taken by Xin Zhang. From left to right: Lucila Rey Ares (EOWG Liaison), Rachel Tan, Joshua Bonsel (Former Co-chair), Yiting Luo, Ai-Ping Chua, Jia Jia Lee (current Network Chair), Haode Wang, Akanksha, Stevanus Pangestu (Network Vice Chair), Guangjie Zhang, Ling Jie Cheng, Jan Faller, Alexander van Heusden, Yan Li, Jonathan Nazari, and Benjamin Craig (Former Co-chair).

FOUNDING MEMBERS

Giselle Aqwe Abangma, BSc, MSc

giselle.abangma@lshtm.ac.uk (pronouns: she/her/hers)

BIOSKETCH

I have a BSc in pharmaceutical sciences, an MSc in health promotion and public health, and an MSc in health economics. Before commencing my PhD, I worked as an analytical chemist with GlaxoSmithKline, a health economist with the University of Oxford's Health Economics Research Centre (HERC), a health research analyst with Swissre, and briefly as a consultant writer with Open Health. My research focuses on the analysis of EQ-5D data for economic evaluation.

SUPERVISORS (ROLE)

Professor Andrew Briggs BSc (Hons) MSc DPhil (1st supervisor) Andrew Lloyd BSc (Hons) MSc DPhil (2nd supervisor)

YEAR & LOCATION

Expected completion in 2025, Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom

PHD ABSTRACT

The EQ-5D is the most widely used generic instrument to measure, compare and value health status across disease areas. In the UK, the National Institute for Health and Care Excellence (NICE) has specified the EQ-5D as its preferred method of utility measurement and as such has become the cornerstone of Health Technology Appraisal (HTA) affecting important decisions about access to new medicines. Despite all this, EQ-5D data are often under-reported, and inadequately analysed. As such, the main aim of the PhD is to explore the analysis of EQ-5D data for economic evaluation.

The main aim of this project is likely to cover the following key research questions.

- Uncertainty around EQ-5D values used in cost effectiveness analysis and methods to address them
- The concept of minimally important difference for a generic HRQoL instrument such as the EQ-5D
- Informative missingness of EQ-5D data when health fluctuates
- Impact of different modelling methods on EQ-5D data.
- Explore the use of the visual analogue scale component of the instrument to enhance analyses of the tariff values.

This research project will seek to extend the existing body of research on the design and analysis of EQ-5D data and add to the EuroQol Group body of research.

EQ GRANTS (ROLE)

Methods for addressing uncertainty around EQ-5D values (PhD student)

WORKING GROUPS

Descriptive Systems, Population & Health Systems

Joshua Michael Bonsel, MD (Former Network Chair)

j.bonsel@erasmusmc.nl (pronouns: he/him/his)

BIOSKETCH

My name is Joshua M. Bonsel, and I am a recent MD (2020, Erasmus University Rotterdam) and MSc in Health Economic, Policy and Law (2020, Erasmus University Rotterdam). Before starting my EuroQol PhD, I have worked as a MD (ANIOS) at GP Emergency Department (March, 2020 - March, 2021) and as MD (ANIOS) at COVID-19, internal medicine, cardiology and gastroenterology wards (November, 2020 - October, 2021). My research interests are mainly Quality of Life in general orthopedics, registry use of EQ-5D/other PROs, and as a "side-project" statistical shape modelling in pediatric orthopedic imaging.

SUPERVISORS (ROLE)

Gouke J. Bonsel, MD, PhD (co-supervisor)
Max Reijman, PhD (co-promotor)
Jan A.N. Verhaar, MD, PhD (promotor)
M.F. Janssen, PhD (co-supervisor)

YEAR & LOCATION

Expected completion in 2024, Orthopedic Surgery, Medicine, Erasmus University Rotterdam, Zuid-Holland, The Netherlands

PHD ABSTRACT

In this PhD-project the potential of EQ-5D in Orthopedics is demonstrated, thereby enhancing use of the Dutch arthroplasty registry. The proposed research program not only enables a PhD achievement of the candidate, but will also build up an expertise center at the department of Orthopedics at the Erasmus Medical Center on the best use of the EQ-5D, and other available outcome measures. The proposal includes 5 projects.
Working packages:
1) Systematic review on use of PROMs specifically EQ-5D as quality improving tool, with a focus on Orthopedics
2) Using Dutch arthroplasty registry data to show EQ-5D inequalities in Orthopedics
3) Using Dutch arthroplasty registry data to study the impact of COVID-19 in Orthopedics
4) A sub-study from the POPCORN-survey to illustrate the COVID-19 impact in the general population with joint disease

A registry founding project in scoliosis children in which also the performance of the EQ-5D-A is compared to the EQ-5D-Y

EQ GRANTS (ROLE)

- Measuring Quality of Life in Orthopedics, 287-PHD (PhD student); EQ-5D Inequalities in Dutch Orthopaedic patients., 200-2020RA (PhD student)
- Patient Reported Outcomes in Quality of Care. A systematic review with specific attention to barriers and opportunities for EQ-5D in orthopedic surgery, 145-2020RA (PhD student)

WORKING GROUPS

Population & Health Systems, Youth

Ashwini Priyangika De Silva, BBA

apdesilva@student.unimelb.edu.au (pronouns: she/her/hers)

BIOSKETCH

Ashwini is a PhD student at the Melbourne School of Population and Global Health studying the social value of avoiding poor health states in children under the guidance of her principal supervisor, Ashwini holds a Bachelor of Business Administration in Business Economics from the University of Colombo, Sri Lanka and was awarded the Student of the Year 2020 and has previously worked as an Analyst attached to the commercial lending vertical of Acuity Knowledge Partners.

SUPERVISORS (ROLE).

Dr. Tianxin Pan (Principal Supervisor)
Dr. Tessa Peasgood (Co-Supervisor)
Professor Nancy J. Devlin (Co-supervisor)
Professor Kim Dalziel (Co-supervisor)
Professor Richard Norman (External Supervisor)

YEAR AND LOCATION

Expected completion in 2025, Melbourne Health Economics, Centre for Health Policy, Melbourne School of Population Global Health, University of Melbourne, Victoria, Australia

PHD ABSTRACT

The project will explore the relative social value of child versus and adult QALY by analyzing qualitative data on the relative social value of improvements in child health compared to adult health that will be collected within the context of Person Trade off (PTO) and pairwise choice exercise conducted in Australia. The primary objective of this study is to provide useful evidence to decision makers in Australia to understand public opinion on the social value of child health gains relative to adult health gains. The study aims to (1) provide weights for the social value of improvements in both length of life and health-related quality of life for each age from birth to young adulthood (0-24) versus gains to an adult (aged 40), based on the stated preferences of the Australian general public; (2) provide a summary for decision makers of the views of a representative sample of the Australian public and of parents with children with a health condition to understand how they feel about valuing health gains differently based on youth; (3) understand any difference in child vs adult weights between: extending length of life and improving quality of life, improving different domains of quality of life (physical health vs mental health) and extending length of life for 2 years versus 5 years; (4) understand the strength of preference towards physical health gains for patients of different ages relative to any preference for favouring those with a limited life expectancy. Given the increasing use of Absolute Shortfall as a modifier for QALY gains this explores the relative weight to age versus overall length of life; (5) understand whether any preferences derived from trade-off questions are consistent with expression of attitudes in attitudinal questions and understand the reasons for any inconsistencies; (6) test the impact of different study designs relating to including an ‘opt out’ option versus forcing respondents to select a preferred age group within the choice question. Half the sample will be forced to express a preference between groups of patients of different ages within their first question and the other half will be able to express equivalence of value in all questions and (7) check data consistency through a ‘chaining’ test of preferences.

WORKING GROUPS

Valuation, Younger populations

EQ GRANTS (ROLE)

348-PHD

Yifan Ding

y.ding@erasmusmc.nl (pronouns: she/her/hers)

BIOSKETCH

My name is Yifan Ding. I am working as a first-year PhD candidate at the Department of Psychiatry, Erasmus MC, Rotterdam, the Netherlands. I am trying to focus on the topic "improving EQ-5D quality of life instruments for measuring and quantifying disease burden of mental conditions in China", which is also my funded project. The project I am working on now is the bolt-on of EQ-5D in China.

SUPERVISORS (ROLE)

Jan van Busschbach, PHD (Supervisor)
Zhihao Yang, PHD (Co-supervisor)

YEAR & LOCATION

Expected completion in 2025, Department of Psychiatry, Erasmus MC, Rotterdam, Zuid-Holland Province, the Netherlands

PHD ABSTRACT

EQ-5D was found to have a high ceiling effect and be insensitive in detecting differences in health status in China. In recent years, the legitimacy of applying EQ-5D in the Chinese cultural setting has been questioned. Given health can be conceptualized differently in China, it can be argued that EQ-5D may miss some important questions for Chinese populations in describing health.

However, no systematic investigations into this potential issue have been made and what important health dimensions to Chinese but not included in EQ-5D remains unknown.

This study aims to systematically review relevant studies on the Chinese concepts of health and health-related quality of life, in order to identify those important health dimensions in a Chinese cultural setting but have not been included in EQ-5D.

A scoping review will be undertaken to attain the research aim. First, a systematic literature search will be conducted in Chinese databases CNKI and Wanfang, as well as English databases EMBASE, MEDLINE and the EuroQol Asian Academy meeting proceedings. We will review articles on the following topics: 1) reporting HRQoL measures that were developed in a Chinese cultural setting; 2) constructing a conceptual framework of health or health-related quality of life specifically to Chinese culture; 3) conducting qualitative interviews to explore Chinese people's understandings of health. Second, two bilingual reviewers will screen titles, abstracts and full-text articles independently. Third, data will be extracted and synthesised. Fourth, a list of potentially important health dimensions that are not covered by EQ-5D will be identified.

WORKING GROUPS

Descriptive Systems

Renee Jones, BSci MPH

reneej1@student.unimelb.edu.au (pronouns: she/her/hers)

BIOSKETCH

I am a PhD student with the Health Economics Unit at the University of Melbourne, and my research is focussed on the measurement of paediatric health related quality of life (HRQoL) and paediatric patient reported outcome measures (P-PROMs). I hope to explore the clinical utility of the EQ-5D-Y as a routine PROM in managing clinical care in a tertiary paediatric children's hospital. I have previously completed a Bachelor of Science and Master of Public Health. Prior to starting my PhD in 2022, I was a Research Assistant with the Health Services and Economics group at the Murdoch Children's Research Institute, working across a range of research areas (HRQoL, mental health, asthma, childhood adversity, HTA assessment).

SUPERVISORS (ROLE)

Professor Kim Dalziel, PhD (Primary supervisor) Professor Nancy Devlin, PhD (Co-supervisor)
Professor Harriet Hiscock, MB BS, FRACP, MD, FAAHMS, GAICD (Co-supervisor)
Associate Professor Brendan Mulhern, PhD (Committee member)

YEAR & LOCATION

Expected completion in 2025, Health Economics Unit, Centre for Health Policy, Melbourne School of Population Global Health, University of Melbourne, Victoria, Australia

PHD ABSTRACT

Background: Increasingly clinicians, health service providers and patients see value in the use of patient reported outcome measures (PROMs) to inform clinical practice. As a short generic health measure, validated across a wide age range and with strong psychometric properties, the EQ-5D-Y is a promising tool for routine use as a clinical PROM for children. There is a paucity of research regarding the use of PROMs in children and the use of EQ-5D-Y as a clinical PROM.

Aims: This PhD aims to assess the clinical utility of the EQ-5D-Y as a routine PROM in managing clinical care in a tertiary paediatric children's hospital.

Methods: A knowledge to action framework will inform a four stage, mixed methods approach: 1) assessment of the performance of generic paediatric HRQoL instruments (including EQ-5D-Y) across a range of child age groups, health groups (chronic condition versus acute condition versus general population), and settings (hospital versus community), 2) comparison of paediatric condition specific and generic instruments across a range of child age groups and health groups (chronic condition versus acute condition), 3) co-design preferences for PROM integration with families and clinicians, and 4) pilot two alternative methods of presenting the EQ-5D-Y as a PROM to clinicians and families in a number of tertiary paediatric hospital outpatient clinics.

Relevance for the EuroQol Group: Develop guidance for extended and sustained use of EQ-5D-Y in tertiary paediatric practice, including international extensions.

EQ PAPERS (DOI)

doi.org/10.1007/s40273-023-01330-2
doi.org/10.3390/children10101604
doi.org/10.3390/children8080714

EQ GRANTS (ROLE)

Evaluation of the EQ-5D-Y as a child PROM in tertiary hospitals for high impact childhood conditions, 330-PHD (PhD student)

WORKING GROUPS

Population & Health Systems, Youth, Education & Outreach

Maksat Jumamyradov

maksat@usf.edu (pronouns: he/him/his)

BIOSKETCH

I acquired my undergraduate degree in Public Finance at Istanbul University in 2011. Since 2017, I have been pursuing my PhD degree in Economics at the University of South Florida. I am a research assistant, and my fields of interest are Econometrics, Health economics and Industrial Organizations. I published an article titled "Biases in Maximum Simulated Likelihood Estimation of Bivariate Models" with Dr Murat Munkin.

SUPERVISORS (ROLE)

Murat Munkin, PhD (Advisor)
Benjamin M. Craig, PhD (Advisor)

YEAR & LOCATION

Expected completion in 2024, Economics, College of Arts and Science, University of South Florida, Tampa, USA

PHD ABSTRACT

This proposal has two objectives towards investigating the performance of the maximum simulated likelihood (MSL) estimator and comparing its performance to the Bayesian estimator. First, Jumamyradov and Munkin (2020) show that the MSL estimator leads to serious inferential biases under the bivariate normal and bivariate Poisson models. I will apply a similar approach to investigate the performance of the MSL estimator under the mixed logit model with and without inter-alternative correlations. Second, I will compare the performance of the maximum simulated likelihood (MSL) and Bayesian Markov chain Monte Carlo (MCMC) estimators under different specifications of the mixed logit model. I hypothesize that their relative performance depends on the specification, namely the number of random parameters and various taste patterns. I will also analyze how the MSL estimator performs in presence of random ancillary parameters that account for scale and discount heterogeneity. There are two main aims of this proposal: (1) Investigate the performance of the maximum simulated likelihood (MSL) estimator in (1a) the bivariate normal and Poisson models, and (1b) the trinomial logit model with inter-alternative correlations (substitution patterns) that violate the independence from irrelevant alternatives (IIA) property. (2) Compare the performance of the MSL and Bayesian estimators of the hierarchical-mixed logit model using simulated and empirical panel data (2a) with different numbers of independent random coefficients (2b) under different specifications of random coefficients (taste patterns) (2c) with random parameters that account for scale and discount heterogeneity.

EQ PAPERS (DOI)

doi.org/10.1515/jem-2021-0003 doi.org/10.3390/econometrics11010004 doi.org/10.1136/bmjopen-2023-077256

EQ GRANTS (ROLE)

- Sequential relief of child health problems, 304-PHD (PhD student)
- Fast-Track Proposal: SCRAP in Health Valuation, 207-2020RA (PhD student)

WORKING GROUPS

Valuation, Health & Wellbeing

Jia Jia Lee, MPH (Network Chair)

lee.jia.jia@u.nus.edu (pronouns: she/her/hers)

BIOSKETCH

Jia Jia LEE is a PhD student under the supervision of Dr Nan LUO at the Saw Swee Hock School of Public Health, NUS. She completed MPH at the SSHSPH, NUS and has years of working experience in clinical research. Her research areas focus on quality of life, medical decision-making, and the development of patient decision aids. She is working on her PhD project funded by the Euroqol Research Foundation which is titled "An EQ-5D-based decision aid for bariatric surgery".

SUPERVISORS (ROLE)

Nan Luo, PhD (Advisor)
Asim Shabbir, MBBS (PAK.), MMed (S'pore), FRCS (Edin.) (Co-advisor)
Nick Bansback, PhD (Co-advisor)
He Hong-Gu, Linda, PhD, MScN, BScMed, RN, MD, FAAN (Chairperson)

YEAR & LOCATION

Expected completion in 2026, Saw Swee Hock School of Public Health, National University of Singapore (NUS), Singapore

PHD ABSTRACT

Background: The low utilization rate of bariatric surgery (BS) and the decision dissonance among BS recipients suggest that the current decision quality is suboptimal. The existing patient decision aids (PtDAs) for BS focuses on clinical outcomes. Information about health-related quality of life (HRQoL) following BS is absent. The existing PtDAs also lack a decision-making tool that helps the users make a decision that aligns with their personal values. A PtDA with both the clinical benefits and changes in HRQoL could potentially help patients considering BS make a quality decision.
Aim: To explore the potential of an EQ-5D-based PtDA in improving decision-making of individuals considering BS.
Methods:
Study 1: Qualitative interviews involving patients considering/having rejected/received BS and healthcare professionals who provide consultation/counselling to obese patients considering BS.
Study 2: Clinical and demographic data and routinely collected EQ-5D data of BS recipients will be analyzed to identify the preoperative predictors of
post-operative EQ-5D outcomes.
Study 3: A cross-sectional study will be conducted with adult patients who are qualified for BS but were on non-surgical treatment to understand the baseline predictors and the magnitude of improvement in EQ-5D outcomes 3-6 months post-treatment.
Study 4: A web-based PtDA will be developed based on the findings from Studies 1 and 2.
Study 5: The effectiveness of the PtDA will be pilot-tested by comparing a comparison arm and an intervention arm.
This project echoes the aim of the Population and Health Systems Working Group by promoting and enhancing the use of EQ-5D as the major component of a PtDA for patients considering BS. This research would generate scientific evidence about the application of EQ-5D data collected in routine clinical practice to facilitate shared decision-making and to translate into enhanced clinical and patient-reported outcomes.

EQ PAPERS (DOI)

doi.org/10.1186/s12955-016-0477-8

EQ GRANTS (ROLE)

An EQ-5D-based decision aid for bariatric surgery, EQ Project 439-PHD (PhD Student)

WORKING GROUPS

Population & Health Systems

Meixia Liao, MSc

meixia.liao@u.nus.edu (pronouns: she/her/hers)

BIOSKETCH

Meixia Liao is currently a PhD candidate in Saw Swee Hock School of Public Health, National University of Singapore. She received her Master of Science in Management Science from Tsinghua University and Bachelor of Arts in Economics from Peking University, China. Her research interests are in valuation of health and quality of life, patient-reported outcomes, and economic evaluation.

SUPERVISORS (ROLE)

Nan Luo, PhD (Main Thesis Advisor)
Kim Rand, PhD (Co-Advisor)
Zhihao Yang, PhD (Co-Advisor)
Milad Karimi, PhD (Co-Advisor)

YEAR & LOCATION

Expected completion in 2025, Saw Swee Hock School of Public Health, National University of Singapore, Singapore

PHD ABSTRACT

In cost-effectiveness analysis, health outcomes are measured using a utility scale where 1 corresponds to full health, 0 corresponds to being dead, and negative values for worse-than-dead (WTD) health states. While health-state valuation methods have advanced significantly in the past decades, they do not work well in measuring the utility of very poor health outcomes. This project aims to explore new methods for the valuation of very poor health outcomes for cost-effectiveness analysis of health technologies.

The project will apply mixed methods and analyse both primary and secondary data. Briefly, a total of four studies are planned. Study 1 is an investigation into censoring issue of composite time trade-off (cTTO) tasks using a time-based willingness-to-accept question. Study 2 is a qualitative investigation of the thought processes for valuing WTD health states in cTTO tasks. Study 3 and 4 is an empirical testing of a novel TTO method which uses the pits state ‘55555’ as the anchor state (referred to as ‘pTTO’).

The project is expected to contribute to knowledge on the challenges in eliciting negative health-state utility. The new TTO methods are expected to improve valuation of WTD health states for cost-effectiveness analysis of health technologies.

EQ PAPERS (DOI)

- doi.org/10.1016/j.jval.2024.05.009
- doi.org/10.1007/s10198-024-01714-x
- doi.org/10.1007/s11136-022-03329-2
- doi.org/10.1007/s11136-023-03394-1

EQ GRANTS (ROLE)

- Improving valuation of very poor health outcomes for cost-effectiveness analysis of health technologies, 76-2020RA (PhD student)
- Vision, hearing, sleep, fatigue/energy and social relationships bolt-ons for the EQ-5D-3L and EQ-5D-5L: a systematic review, 1703-RA (Co-investigator)

WORKING GROUPS

Valuation, Population & Health Systems

Rachel Lee-Yin Tan, BA

racheltanleeyin@u.nus.edu (pronouns: she/her/hers)

BIOSKETCH

My research interest lies in HRQoL measurement and health services research, with focus on children's health. I have a background in psychology having graduated from the University of British Columbia with a BA (Hons). As a PhD student with the National University of Singapore, I received specific training on survey design, program effectiveness analysis, and patient-reported outcomes assessment. My PhD thesis aims to make available a local child and adolescent preference-based measure.

SUPERVISORS (ROLE)

Nan Luo, B.Sc., M.Sc., Ph.D. (Supervisor)
Kavita Venkataraman, MBBS, PG DHA, PhD (Chair)
Mihir Gandhi, CSci, CStat, PhD (Co-chair)

YEAR & LOCATION

Expected completion in 2024, Health Systems and Behavioural Sciences, School of Public Health, National University of Singapore (NUS), Singapore

PHD ABSTRACT

Preference-based measures (PBMs) for measuring health-related quality of life (HRQoL) provide a convenient approach to derive health state values for the calculation of quality-adjusted life-years (QALYs) needed for cost-utility analysis (CUA) of health interventions or technologies. HRQoL data generated from PBMs can also be used to estimate the humanistic disease burden of paediatric conditions. To date, no such instrument has been made available for use in paediatrics in Singapore. EQ-5D-Y is a PBM suitable for use by children and adolescents. EQ-5D-Y has demonstrated good measurement properties in multiple paediatric populations. However, whether the EQ-5D-Y is valid, reliable and responsive in Singapore is unknown. In addition, no value set has been developed for EQ-5D-Y for use in the local context. Local value sets are preferred for calculation of QALYs in CUA. The overall aim of my project is to make preference-based HRQoL instruments available for use in paediatrics in Singapore. The specific aims of the project are: 1) to culturally adapt EQ-5D-Y or use in paediatrics in Singapore; 2) to assess measurement properties including validity, reliability, and feasibility of EQ-5D-Y in children and adolescents with asthma and eczema in Singapore; 3) to develop a local EQ-5D-Y value set for use in Singapore. The project will be conducted in two phases. In the first phase, EQ-5D-Y will be culturally adapted for use in Singapore following the standardised translation protocol provided by the EuroQol Group. In the second phase, validation of the EQ-5D-Y in children and adolescents with asthma and eczema will be conducted. Concurrently, valuation will be done for EQ-5D-Y in the local public to develop an EQ-5D-Y value set for use in Singapore following the EQ-5D-Y valuation protocol recommended by the EuroQoL Group.

EQ Papers (DOI)

- doi.org/10.1016/j.jval.2021.02.003
- doi.org/10.1007/s40273-019-00854-w
- doi.org/10.1007/s40271-020-00452-5
- doi.org/10.1007/s40271-020-00466-z
- doi.org/10.1007/s40271-018-00354-7
- doi.org/10.1007/s11136-020-02644-w
- doi.org/10.1007/s10198-019-01156-w
- doi.org/10.1007/s10198-022-01479-1
- doi.org/10.1007/s40271-020-00452-5

EQ Grants (Role)

-

Working Groups

Descriptive Systems, Valuation, Population & Health Systems, Youth, Health & Wellbeing

Abraham Gebregziabiher Welie, MSc

abrishg20@gmail.com (pronouns: he/him/his)

BIOSKETCH

His educational background includes a Master of Science degree in pharmacoepidemiology and social pharmacy from Addis Ababa University and a Bachelor of Pharmacy from Mekelle University. His work experience includes serving as a lecturer and head of a course on pharmacoepidemiology and social pharmacy and leading a research team at Mekelle University. His research interests include the use of health-related quality of life and cost-effectiveness to evaluate health technologies in Ethiopia.

SUPERVISORS (ROLE)

Feng Xie, PhD (Supervisor), Elly Stolk, PhD (Co-supervisor)

YEAR & LOCATION

Expected completion in 2026, Health Research Methodology, Faculty of Health Science, McMaster University, Hamilton, Canada

PHD ABSTRACT

The goal of this PhD project is to improve health measurement and valuation for children and adolescents in Ethiopia. Specific objectives include: To compare psychometric performance of two measures of child health (EQ-5D-Y-3L and -5L); To explore whether the measurement properties are sustained across modes of administration self-report (interviewer assisted and self-complete), and proxy report); To generate an EQ-5D-Y-3L value set, reflecting how good or bad different child health states are according to the Ethiopian adult and adolescent population using the international valuation protocol; And to investigate whether children experiencing a heath state and adults have the same idea about how good or bad those outcomes are.

The Ethiopian Federal Ministry of Health has introduced a public health insurance system and aims to support healthcare financing with principles of HTA. The current practice of HTA for regulatory and formulary development is based on expert opinion and published HTA studies from other countries. This recent development of the HTA system recommends the use of societal preferences for valuing health states and social health insurance. However, local value sets are not yet available for children and adolescents. Therefore, there is a rising need for research on youth health measurement and valuation in this country.

EQ PAPERS (DOI)

- doi.org/10.1016/j.vhri.2019.08.475;
- doi.org/10.1007/s10198-021-01412-y;
- doi.org/10.1371/journal.pone.0264199

EQ GRANTS (ROLE)

Valuing Health-State: An EQ-5D-5L Value Set for Ethiopians, 20170480 (PI); Feasibility, reliability and validity of using EQ-5D-Y-5L among healthy and adolescents with major mental disorders in Ethiopia, 20180500 (PI); Psychometric properties, feasibility and usefulness of the extended EQ-5D-Y-5L in children with prevalent disease conditions in Ethiopia, 20191010 (PI); Assessment and comparison of the feasibility and measurement properties of the EQ-5D-Y-3L and EQ-5D-Y-5L self-complete versions in the Tigrinya language and comparison with the CHU-9D, 133-2020RA (Co-PI); Investigating the aspects of HRQoL covered by pain/discomfort and the added value of the psoriasis bolt-ons (EQ-PSO) among patients suffering from skin diseases, 89-2020RA (PI); Investigating the impact of transitioning from EQ-5D-Y to the EQ-5D descriptive system, in a group of adolescents with different health conditions, 147-2020RA (PI); Assessing and comparing psychometric properties of both 3L/5L of EQ-5D-Y and adult EQ-5D versions in adolescents with prevalent disease conditions in Ethiopia, 225-2020RA (PI); Agreement of the Amharic EQ-5D-Y-3L and Y-5L self-report (by interview-administration and self-complete) and proxy-report, 340-2020RA (PI)

WORKING GROUPS

Youth

Jiajun Yan, MSc

yanj89@mcmaster.ca (pronouns: he/him/his)

BIOSKETCH

Jiajun is a PhD candidate in Health Technology Assessment at McMaster University. He holds an MSc in Biostatistics from University of Toronto and a BS in mathematics. Prior to his PhD, Jiajun had worked as a biostatistician responsible for clinical trial design and analysis in the pharmaceutical industry for a number of years. He is interested in economic evaluations and analysis of patient-reported outcomes.

SUPERVISORS (ROLE)

Feng Xie, PhD (Supervisor)
Eleanor Pullenayegum, PhD (Committee member)
Shun Fu Lee, PhD (Committee member)

YEAR & LOCATION

Expected completion in 2024, Health Research Methods, Evidence and Impact (HEI), McMaster University, Toronto, Canada

PHD ABSTRACT

There is a growing interest in measuring patient-reported outcomes (PROs) in clinical research. The EQ-5D-5L has been often included to supplement disease-specific PRO instruments in randomized clinical trials (RCTs). The EQ-5D-5L data, if analyzed properly, can produce important evidence for two purposes: estimating the treatment effect between arms and deriving health utilities to support economic modeling. However, the analysis and reporting of the EQ-5D-5L in RCTs is rather limited, due at least in part to the lack of methodological guidance in analyzing utility data. Among those RCTs with published EQ-5D data, there is noticeable heterogeneity in choosing statistical models for data analyses. This PhD project aims at producing empirical evidence in comparing a wide range of statistical models in estimating treatment effect using the EQ-5D-5L and deriving health utilities for economic models. Furthermore, the output from this research program can be used to develop practical guidances on analyzing the EQ-5D-5L in the RCT setting. Such guidances can potentially improve the quality of analyzing and reporting the EQ-5D-5L in this context.

EQ GRANTS (ROLE)

Statistical methods for analyzing EQ-5D-5L data in randomized clinical trials, 345-PHD (PhD Candidate)

WORKING GROUPS

Education & Outreach

Guangjie Zhang, BSc

g.zhang@erasmusmc.nl (pronouns: she/her/hers)

BIOSKETCH

From 2020, I began to study Pharmacoeconomics in Jinan University. In this year, I attended a research on setting a valuation index for EQ-5D-Y in Chinese Population.From then on, I started my research journey on EQ-5D field. I conducted research on measuring Health-related quality of life in clinical treatment and on the face validity of EQ-HWB in the Chinese population. In September, I will begin to study health economics comprehensively at Aberdeen University.

SUPERVISORS (ROLE)

Jan van Busschbach, PhD (Promoter)
Zhihao Yang, PhD (Co-promoter)

YEAR & LOCATION

Expected completion in 2027, Medical Psychology and Psychotherapy, Erasmus Medical Centre, Erasmus University Rotterdam, Rotterdam, the Netherlands

PHD ABSTRACT

EQ-HWB is a new generic instrument designed to capture health outcomes in mental diseases, well-being and social care. Additionally, it has the potential of generating QALY for conducting research in health economics. Given that EQ-HWB is developing, therefore, it still needs to conduct research on psychometric properties and to conduct a variety of research. On the other hand, the Chinese have a different concept of health and there is not much research on exploring Chinese populations' psychological characteristics. Hence, I want to conduct some research on measuring health concepts, on psychometric properties of EQ-HWB. Furthermore, I want to research psychological characteristics in different ages and areas in the Chinese population by combining EQ-5D-5L and EQ-HWB.

WORKING GROUPS

Health & Wellbeing

Wenjing Zhou, MSc

w.zhou.1@erasmusmc.nl (pronouns: she/her/hers)

BIOSKETCH

Wenjing Zhou started her PhD programme at Erasmus University Rotterdam in September 2021. Her research Interests focus on the impact of health-related quality of life and outcome of chronic diseases in children in China. She got the BSc and MSc at Shanghai Jiaotong University, majoring in clinical medicine. She has been working as a pediatrician since 2008 in the department of Pediatrics, Shanghai Renji Hospital, China, mainly engaged in pediatric allergic diseases and rheumatic diseases. From 2018, as a visiting scholar, she studied at National University of Singapore, under the supervision of Professor Nan Luo. Since then, she has been working on the validation of EQ-5D-Y.

SUPERVISORS (ROLE)

Jan Busschbach, PhD (Promotor)
Nan Luo, PhD (Co-promotor)
Zhihao Yang, PhD (Co-promotor)

YEAR & LOCATION

Expected completion in 2025, Department of Psychiatry, Section Medical Psychology and Psychotherapy, Erasmus Medical Centre, Erasmus University Rotterdam, Rotterdam, The Netherland

PHD ABSTRACT

The EQ-5D is the world's leading instrument to measure health related quality of life in health economic evaluations of health care interventions. Health economic evaluations are used in health care policy aimed at increasing the effectiveness of health care and to reduce differences in health between populations (equity). We propose to work with the EuroQol Group to deliver a state-of-the-art EQ-5D questionnaire (youth version, EQ-5D-Y) suitable for use by children and adolescents in China. This instrument will aim to produce valid quality of life values of children and adolescents in China that can be used in health economic evaluations. This would be of great significance as there is a growing need to assess the cost-effectiveness of health interventions for young populations. It will also push the scientific development of the EQ-5D in China to the international frontier of the sciences. This PhD project aims to identify 3 research questions which are relevant to China and the EuroQol Group in validating the new version of the EQ-5D: 1) What are the psychometric prosperities, specifically, validity and reliability, of the Chinese version of EQ-5D-Y for China in children and adolescents? 2) How should existing valuation methods be adapted for use in the Chinese low aged population? How does the EQ-5D-Y proxy version perform in these populations? 3) Can the instrument produce valid quality of life values of children and adolescents in China that can be used in health economic evaluations, specifically in children with chronic diseases such as haematological malignancies, juvenile rheumatic diseases and allergic diseases?

EQ PAPERS (DOI)

doi.org/10.1007/s10198-021-01309-w

WORKING GROUPS

Youth

MEMBERS AS OF JANUARY 2023

Akanksha Akanksha, BDS MPH

akanksha.akanksha@student.uts.edu.au (pronouns: she/her/hers), Australia

BIOSKETCH

I am a final year PhD student at Centre of Health Economics Research and Evaluation (CHERE), University of Technology Sydney (UTS), Sydney, Australia. I completed my Bachelor in Dental Surgery and Master in Public Health before starting my PhD. I am interested in quality of life research and health technology assessment. I have worked as an academic tutor in epidemiology and population health research. Currently I work as a part-time health economist at CHERE alongside doing my PhD.

DOCTORAL PROGRAM

Centre for Health Economics Research and Evaluation, Faculty of Health, University of technology Sydney, New South Wales, Australia, Expected completion in 2025

SUPERVISORS (ROLES):

A/Prof. Brendan Mulhern (Primary supervisor)
Prof. Rosalie Viney (Co-supervisor)
Prof. Deborah Street (Co-supervisor)

PHD ABSTRACT

Economic evaluation is an essential tool that guides the way in which scarce health care resources are allocated within the health sector. A Quality Adjusted Life Year (QALY) is a metric that combines length of life and quality of life (QoL); and is used to conduct cost utility analyses (CUA) of healthcare interventions. Assessment of QoL is often more focused on the health-related aspect and other aspects such as social care related QoL (SCRQoL) are often not measured and or not valued enough. My PhD explores the methods for broadening the measurement of QoL by investigating the relationship between health related QoL (HRQoL) instruments like EQ-5D and SCRQoL instruments like Adult Social Care Outcomes Toolkit (ASCOT). Primarily, the PhD work explores statistical mapping methods to map between the two instruments and a combined instrument.

This research work will provide evidence on the impact of using a more holistic instrument for health sector decision making.

EQ GRANTS (ROLE)

1799-RA Psychometric assessment of the EQ-HWB and Comparative Analysis with EQ-5D-5L, AS-COT, and QOL-ACC in the Australian context.” *(Co-Principal Investigator)*

AREA OF INTEREST

Health and Wellbeing, Descriptive Systems, Valuation, Population & Health Systems

Abeer Al Rabayah, BSc, MBA, MSc

Abeer-Ahmad-Hamdan.Al-Rabayah@umit-tirol.at (pronouns: she/her/hers), Jordan

BIOSKETCH

Dr Abeer Al Rabayah is the head of the Center for Drug Policy and Technology Assessment (CDPTA) at the King Hussein Cancer Center (KHCC) and a research associate at UMIT TIROL - University for Health Sciences and Technology, Austria. Abeer holds a BSc in pharmacy, an MBA, and a MSc in International Health Technology Assessment from the University of Sheffield. Her research interests are: decision analytical modeling, HTA processes, health-related quality of life, and outcome valuation studies

DOCTORAL PROGRAM

Dept. of Public Health, Health Services Research and Health Technology Assessment, Institute of Public Health, Medical Decision Making and HTA, UMIT TIROL - University for Health Sciences and Technology, Hall in Tirol , Austria , Expected completion in 2025

SUPERVISORS (ROLES):

Uwe Sibert, Prof. Dr, MPH, MSc (Supervisor)

PHD ABSTRACT

Currently, I am a PhD student at UMIT TIROL - University for Health Sciences and Technology, Austria. My thesis includes interrelated projects with several planned publications. First, conducting a systematic review to describe the use of EQ-5D in Jordan and the region. Second, a valuation study of the EQ-5D-3L to generate a local value set that matches the health state preferences for Jordanians. Finally, an assessment of the impact of the generated Jordanian value set on ICERs and quality of life by demonstrating a practical case example for a cost-effectiveness project and an observational clinical study.

EUROQOL RESEARCH

- Al-Rabayah AA, Al Froukh RF, Al Najjar B, Rayyan M, Salmany S, Iweir S, Nazer L. Quality of Life of Family Caregivers of Critically Ill Patients With Cancer Before and After Intensive Care Unit Admission Measured by EQ-5D 3-Level: A Longitudinal Prospective Cohort Study. Value Health Reg Issues. 2022 Jul;30:39-47. doi: 10.1016/j.vhri.2021.11.003. Epub 2022 Jan 25. PMID: 35086001.
- 60-2020-VS: Generating an EQ-5D-3L value set for the Hashemite kingdom of Jordan, Primary Investigator

AREA OF INTEREST

Valuation, Education & Outreach, Health & Wellbeing

Sally Sansom, BBMed, MPH

sally.sansom@dph.ox.ac.uk, United Kingdom

BIOSKETCH

Sally is a Doctor of Philosophy (DPhil) candidate within the Health Economics Research Centre (HERC) at the University of Oxford, and a Research Fellow within the Centre for Personalised Medicine. Sally's DPhil project is exploring the measurement of outcomes from genome sequencing for rare disease diagnosis in economic evaluations. Sally is grateful to have been awarded a full scholarship in support of her studies funded by the Clarendon Fund Scholarship, Mary Somerville Scholarship, and a Department of Population Health Studentship. Prior to commencing her DPhil, Sally worked for 8-years in roles spanning health economics and strategy consulting, and medical research (including clinical trial) project management. Sally also obtained a Bachelor of Biomedicine (genetics major) from the University of Melbourne, and a Master of Public Health (health economics specialism) from Monash University in Australia.

DOCTORAL PROGRAM

Health Economics Research Centre (HERC), University of Oxford, United Kingdom, Expected completion in 2026

SUPERVISORS (ROLES):

Sarah Wordsworth (BSc, MSc, PhD), James Buchanan (BA, MA, DPhil), Padraig Dixon (BA, MSc, MPhil, DPhil), Michele Peters (BSc, Dip Psych, MSc, PhD)

PHD ABSTRACT

Title: Measuring the outcomes from genome sequencing for rare disease diagnosis in economic evaluations. **Background:** Rare diseases (RDs), while individually rare, collectively affect 6-8% of the general population. Approximately 80% of RDs have a genetic cause, yet diagnosis can take years and require many costly investigations. Genome sequencing is increasingly being used to diagnose RDs and is changing the RD diagnostic paradigm by increasing diagnostic yield and speed. However, the information uncovered by genome sequencing is complex and can impact patients and informal carers across clinical, emotional, cognitive, behavioural, and social outcome domains, which go beyond those typically measured by generic multi-attribute utility instruments (MAUIs). Furthermore, many RDs have no available treatments, so traditional measures such as survival and health-related quality of life (HRQoL) may be difficult to assess. This study aims to determine the generic MAUIs best suited to measuring outcomes from genome sequencing for RD diagnosis. **Methods:** Systematic literature review (SLR) and critical appraisal: Primary studies measuring patient- and carer-reported outcomes from genome sequencing unrestricted by context and published by 16-March-23 were included. Forwards and backwards citation searching was conducted on 15-December-23. Instruments were critically appraised using COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology. Cohort study: Adults undergoing genome sequencing for RD diagnosis and their carers, and carers of children undergoing genome sequencing, will be recruited from three UK National Health Service Genomic Medicine Services from December-2024 to March-2025. Participants will complete quantitative surveys at baseline, and six- and 12-months post-baseline. Qualitative interviews will be conducted after the first follow-up survey. The content validity, construct validity, responsiveness, and feasibility of the administered instruments will be assessed. **Initial conclusions:** Research evaluating the impact of genome sequencing across all contexts has typically focussed on measuring clinical- and emotion-related outcomes, and intermediate outcomes such as diagnostic yield and decision-making. Initial results suggest that generic MAUIs may not be sufficiently relevant or comprehensive for measuring the impact of genome sequencing for RD diagnosis on patients and informal carers. These findings could be used to inform instrument selection and development decisions, and to guide interpretation of results from widely used instruments that under-measure key outcome domains in this context. Overlooking important outcomes from genome sequencing in health technology assessments could result in inefficiencies through delayed or inaccurate diagnoses and lost productivity.

EUROQOL RESEARCH

-

AREA OF INTEREST

Valuation, Population & Health Systems, Health & Wellbeing

Alexander van Heusden, MPH, Bbiomed (Hon)

alex.vanheusden@unimelb.edu.au (pronouns: he/him/his), Australia

BIOSKETCH

I am PhD student at the University of Melbourne (Australia) in the Health Economics Unit. I completed a Master of Public Health and a Honors in Biomedical Science majoring in Human functional Biology, both at the University of Otago. I was awarded the population health prize as the top student during my MPH. I have worked across multiple research projects including: COVID-19 modelling in AUS/NZ, NCD surveillance systems (Thailand), TTO experiments, and sudden cardiac arrest in the young in AUS. I also have two-years of work experience in the forensic services.

DOCTORAL PROGRAM

Health Economics Unit | Centre for Health Policy, Melbourne School of Population and Global Health, the University of Melbourne, Victoria, Australia, Expected completion in 2025

SUPERVISORS (ROLES):

Kim Dalziel, PhD (Primary Supervisor)
Nancy Devlin, PhD (Secondary Supervisor)

PhD ABSTRACT

Few preference-weighted health-related quality-of-life (HR-QoL) measures exist for young children under 5 years of age. Young children are substantial consumers of healthcare services. EuroQoL's EQ-5D-Y is a commonly used preference-based instrument to generate generic health state utility scores and QALYs for children above five, however, there is limited evidence on the acceptability and reliability in children between 2-4 years of age.

Dalziel et al (unpublished) recently conducted a qualitative study where an adapted version of the EQ-5D-Y (3L and 5L) was co-designed through focus groups of parents with young children (aged 2-4) alongside expert input. The findings showed that the adapted EQ-5D-Y has improved relevance and acceptability for 2–4-year-olds and appears easy to complete.

This PhD project will firstly aim to review the psychometric properties of EQ-5D-Y-3L and EQ-5D-5L compared to its most recently adapted version for young children between 2-4 years of age who are administered side by side measures. Secondly, this project aims to conduct think aloud interviews to try to uncover and explore how adults think when asked to conduct discrete-choice experiments (of the above instruments) while thinking about a young child aged 2-4years. Further, assess whether adults with young children are more appropriate to generate a utility value set compared to the general population. Thirdly, the project aims to synthesize the information from the think aloud study to complete a valuation study of the newly adapted EQ-5D-Y-3L/5L. Finally (time permitting), this project aims to explore how we measure a child's HR-QoL as they age and transition across the suite of EuroQoL instruments – ie. Moving from EQ-TIPs (0-3) to the adapted EQ-5D-Y (2-4 years) to the EQ-5D-Y (5+).

EUROQOL RESEARCH

- A qualitative investigation to develop an adapted version of the EQ-5D-Y-3L for use in children aged 2-4 years (In submission)
- 111-2020RA, (PhD student) 361-2020RA, (PhD student)

AREA OF INTEREST

Younger Populations, Valuation, Population & Health Systems

Hannah S. Hussain, MPharm, MSc

hhussain@ohe.org (pronouns: she/her/hers), United Kingdom

BIOSKETCH

I have a Master's of pharmacy degree, and an MSc in health economics and health policy. Before enrolling on my PhD, I worked as a research associate at the centre of health economics at the University of Manchester (MCHE). During my time at MCHE, I worked on several clinical trials, including an international multi-centre trial of a non-pharmacological intervention for people living with dementia (PlwD). I am also a registered and practicing community pharmacist. Since enrolling on my PhD at the University of Sheffield, I have concurrently worked on several wider projects, including interviewing for the new EuroQol instrument - EQ-HWB (EQ Health and Wellbeing instrument) and an internship with DementiaUK. My PhD research is focused on how best to capture EQ-5D in dementia studies for use in economic evaluations.

DOCTORAL PROGRAM

Faculty of Medicine, Dentistry and Health, School of Health and Related Research, University of Sheffield, United Kingdom, Expected completion in 2024

SUPERVISORS (ROLES):

Allan Wailoo, PhD (Primary supervisor)
Anju Keetharuth, PhD (Supervisor)
Donna Rowen, PhD (Supervisor)

PHD ABSTRACT

EQ-5D is widely used to capture health-related quality of life, and through systematic reviewing, is shown to exhibit strong psychometric properties for use in dementia populations. However, as a person living with dementia's condition progresses, their ability to accurately self-report becomes more challenging - leading to a reliance on proxies. It is well established that PlwD-self and proxy reported EQ-5D do not align, particularly for the more "subjective" dimensions, and at the more severe stages of dementia. Therefore, the key issue is that the extent to which either proxy or patient reports reflect "true" utility is likely to differ by disease severity. Data from three existing dementia trials has been acquired for secondary data analyses. The key objectives of this PhD thesis are to: 1) produce a guideline on how best to collect quality of life data in dementia trials and studies, focusing on pragmatic factors, 2) use statistical mapping techniques to map from proxy rated EQ-5D to the equivalent PlwD-self rated values in an attempt to retain people living with dementia as central in the discussion, where self-ratings may no longer be feasible, and 3) use psychometric techniques i.e., IRT and Rasch analysis to understand which EQ-5D dimensions are responded to differently by people of different characteristics, mainly focusing on disease severity

EUROQOL RESEARCH

- Keetharuth, A.D., Hussain, H., Rowen, D. et al. Assessing the psychometric performance of EQ-5D-5L in dementia: a systematic review. Health Qual Life Outcomes 20, 139 (2022). https://doi.org/10.1186/s12955-022-02036-3
- Hussain, Hannah, Anju Keetharuth, Donna Rowen, and Allan Wailoo. Convergent validity of EQ-5D with core outcomes in dementia: a systematic review. Health and Quality of Life Outcomes 20, no. 1 (2022): 1-18. https://rdcu.be/cWx3l

AREA OF INTEREST

Valuation, Health & Wellbeing

Ademola Joshua Itiola, B.Pharm, MPH, MSc (Network Vice Chair)
itiola@ualberta.ca (pronouns: he/him/his), Canada

BIOSKETCH

Ademola is originally from Nigeria and is a pharmacist by training. He holds a Bachelor of Pharmacy Degree (with distinctions) from the University of Ibadan, Nigeria, coupled with a Master of Science Degree in Population and Public Health from The University of British Columbia, Canada, Master of Public Health Degree, and a fellowship in Public Health Pharmacy from West African Postgraduate College of Pharmacists. He is currently enrolled as a PhD student at the University of Alberta, Canada.

DOCTORAL PROGRAM

School of Public Health, University of Alberta, Alberta, Canada, Expected completion in 2025

SUPERVISORS (ROLES):

Jeffrey Johnson, PhD (Chair)

PHD ABSTRACT

Many health care systems are increasingly considering the patient's voice in assessing quality of care. Like many other healthcare interventions, knee replacement surgery is one of the procedures where patient-reported outcomes are more and more important. Osteoarthritis, the major reason for knee replacement surgery, affects over 15% of Canadians, mostly women, the elderly, and low-income earners. Of patients with osteoarthritis, nearly one in five will require surgery. However, almost one-third of individuals who have surgery will be dissatisfied with their outcomes partly due to unmet expectations. To help patients make better decisions, and ensure realistic expectations before surgery, an individualized patient decision aid that considers patients' perspectives has been developed. Patients who used this decision aid have been shown to have twice the odds of making quality decisions than those who did not. Plans are now underway to integrate this decision aid into all bone and joint clinics in Alberta. However, it is unknown if the decision aid is suitable for large-scale routine use in its current form. Also, further evidence of its effectiveness is required to justify its continued routine use and potential scale up to other jurisdictions in Canada and beyond. To bridge this evidence gap, my research aims first to generate updated evidence on the effectiveness of measures that consider patients' assessment of their health in improving the quality of care. The updated decision aid will be subjected to usability testing to determine if further adaptation is needed. Lastly, the effectiveness of the decision aid will be evaluated once introduced into large-scale routine care. Overall, this research will provide evidence on quality-of-care domains mostly impacted by measures that consider patients' health assessment and how effectiveness studies can be improved. Findings will also inform a fit-for-routine-use decision aid and can inform the scale-up of the decision.

EUROQOL RESEARCH

-

AREA OF INTEREST

Valuation, Population & Health Systems, Education & Outreach, Health & Wellbeing

Diana Khanna, B.D.S. (India), M. HEcon (Australia)

khan0420@flinders.edu.au (pronouns: she/her/hers), Australia

BIOSKETCH

As a PhD student at Flinders University, Australia, I am investigating proxy vs child discrepancies in the measurement of paediatric health related quality of life (HRQoL) and the self-report capacity in children using generic preference-based instruments including the
EQ-5D-Y-3L. Prior to this, I completed my master's degree in Health Economics at the University of Queensland (UQ) with high distinction. Working as a Research Assistant has been a part of my past and present work experience.

DOCTORAL PROGRAM

Caring Futures Institute, College of Nursing and Health Sciences, Flinders University, SA, Australia, Expected completion in 2023

SUPERVISORS (ROLES):

Julie Ratcliffe, BA (Hons), MSc, PhD (Professor, Health Economics)
Jyoti Khadka, B Opt, M Phil, PhD (Senior Research Fellow)
Christine Mpundu-Kaambwa, BA, MSc, PhD (Research Fellow)

PHD ABSTRACT

Background: In health economics, generic preference based HRQoL instruments are commonly applied and self-assessment of HRQoL by the person themselves is preferred wherever possible. However, obtaining valid self-assessments of HRQoL in paediatric populations is challenging, particularly during the early stages of childhood and for children with a range of physical, intellectual and/or behavioural impairments. As a result, proxy (parent and/or healthcare professional) assessments of HRQoL are frequently utilised instead of child self-assessments.

Aims: This research will apply a novel mixed methods approach incorporating qualitative think aloud and a quantitative eye tracking approach to investigate: [1] the feasibility and acceptability of child self-assessment of HRQOL for a community-based sample of children aged 6-12 years [2] the concordance between child self and parent proxy assessments of childhood HRQoL using three generic HRQoL measures designed for application in paediatric populations including the EQ-5D-Y-3 L. Methods: A primary cross-sectional study will be conducted through a series of face-to-face semi-structured interviews with parent and child dyads (ages 6-12; N=85 dyads) including children living with and without a variety of health conditions and children from lower and higher socio-economic backgrounds. A mixed methods approach will be developed and applied to facilitate a detailed investigation of the feasibility and acceptability of child self-assessment of HRQOL and the level of child and parental agreement in the measurement of the HRQoL of the child using innovative eye-tracking technology and a qualitative 'think aloud' approach. Outcomes: This research will add significant new knowledge and contribute to methods of best practice and guidance for informing self and proxy assessment of children's HRQoL for economic evaluation and quality assessment.

EUROQOL RESEARCH

- Khanna, D., Khadka, J., Mpundu-Kaambwa, C. et al. Are We Agreed? Self- Versus Proxy-Reporting of Paediatric Health-Related Quality of Life (HRQoL) Using Generic Preference-Based Measures: A Systematic Review and Meta-Analysis. PharmacoEconomics 40, 1043–1067 (2022). https://doi.org/10.1007/s40273-022-01177-z

AREA OF INTEREST

Descriptive Systems, Younger Populations

Yiting Luo, MPH, BS

yiting.luo@student.uts.edu.au (pronouns: she/her/hers), Australia

BIOSKETCH

Yiting Luo is currently a PhD student in the Centre for Health Economics Research and Evaluation at University of Technology Sydney. She has a Master of Public Health degree specializing in Applied Biostatistics from Columbia University and had been working as an epidemiologist focused on chronic diseases prevention from 2018 to 2020. Her research interests are measurement and valuation of pediatric health-related quality of life and discrete choice experiments (DCEs).

DOCTORAL PROGRAM

Centre for Health Economics Research and Evaluation, Faculty of Health , University of Technology Sydney , New South Wales , Australia, Expected completion in 2025

SUPERVISORS (ROLES):

Brendan Mulhern, PhD (Associate Professor)
Deborah Street, PhD (Professor)
Rosalie Viney, PhD (Director, Professor)

PHD ABSTRACT

Conventional methods of valuing adult preference-based measures need to be adapted for use in the valuation of pediatric generic preference-based measures (GPBMs). Methodological issues have been discussed in many literatures around how to value pediatric preference-based measures, for example, whose preferences (child/adolescent, parent, or taxpayer), what appropriate formats for the questionnaire are, and which perspectives should be used (self or other). Further work is required to understand this, and also the ability of the target population to comprehend and complete the valuation tasks. The aim of the PhD project is to explore how pediatric populations choose between various aspects of health as included in a number of widely used GPBMs. This will be done using online Discrete Choice Experiments (DCEs).

Results will help to strengthen the tools used to evaluate health outcomes to inform healthcare decision-making in pediatric populations. The PhD project is part of the QUality OF Life in Kids: Key evidence to strengthen decisions in Australia (QUOKKA) program.

EUROQOL RESEARCH

- Yiting Luo, Brendan Mulhern, Richard Norman, Deborah Street, Rosalie Viney. POB4 Effect of demographic characteristics on health states valuation based on TTO and DCE
- Yiting Luo, Brendan Mulhern, Richard Norman, Deborah Street, Rosalie Viney. POC1 How have qualitative methods been used to understand the valuation of preference-based measures? A scoping review

EQ GRANTS (ROLE)

- 2036-RA Exposure and psychological responses to climate change and their association with EQ-5D: a secondary data analysis from the POPCORN study (Principal Investigator)
- 1867-RA Assessment of the use of EQ-5D and other generic health-related quality of life measures to evaluate the health outcomes associated with extreme weather events and related climate change impacts: A systematic review (Principal Investigator)

AREA OF INTEREST

Valuation, Younger Populations, Population & Health Systems

Jonathan Nazari, PharmD

jnazari2@uic.edu (pronouns: he/him/his), USA

BIOSKETCH

Jonathan Nazari is a PhD student in the Department of Pharmacy Systems, Outcomes, and Policy at the University of Illinois Chicago (UIC) and 2021-2023 UIC/Pfizer fellow in health economics and outcomes research. His research interests include measurement of health-related quality of life and other health outcomes, including in pediatric populations. He previously earned his doctor of pharmacy (PharmD) and Bachelor of Science (BS) in Biochemistry degrees from UIC.

DOCTORAL PROGRAM

Pharmacy Systems, Outcomes, and Policy, College of Pharmacy, University of Illinois Chicago, Illinois, USA, Expected completion in 2025

SUPERVISORS (ROLES):

A. Simon Pickard, PhD (Advisor and Chair)
Ning Yan Gu, PhD (Committee Member)

PHD ABSTRACT

I am currently a co-investigator for the EQ-5D-Y-3L valuation study in the US (Co-PIs: Simon Pickard and Ning Yan Gu; #409-RA). I presented our preliminary work of engaging US stakeholders in a roundtable discussion at the 2022 Plenary meeting. Relatedly, I am investigating data quality and sources of preference heterogeneity among adolescent respondents to DCE valuation tasks. I am also interested in alternative approaches to anchoring DCE-derived latent scale values onto the QALY scale, including alternative preference elicitation methods to cTTO in valuing child and adolescent health related quality of life. This research has implications for end-users of EQ-5D-Y-3L value sets in the context of economic evaluation and health technology assessment, and may inform valuation protocols for future youth instruments.

EUROQOL RESEARCH

- Nazari, J.L., Pickard, A.S. & Gu, N.Y. Findings from a Roundtable Discussion with US Stakeholders on Valuation of the EQ-5D-Y-3L. PharmacoEconomics (2022). https://doi.org/10.1007/s40273-022-01222-x
- Nazari, J.L, Kuharic, M, Pickard, A.S. PCR163 Determination of the Ideal Number of Response Levels for the EQ-5D As a US Population Health Measure. Value in Health, Volume 25, Issue 7, S572/ https://doi.org/10.1016/j.jval.2022.04.1506
- 409-RA: Developing a value set for the EQ-5D-Y-3L in the United States, Co-Investigator

AREA OF INTEREST

Descriptive Systems, Valuation, Younger Populations

Irene Salvi, MSc

irene.salvi@unisg.ch (pronouns: she/her/hers), Switzerland

BIOSKETCH

Irene Salvi is a PhD candidate and research assistant at the Chair of Health Care Management of the University of St. Gallen. After completing her Master degree in Economic and Social Sciences at Bocconi University, she worked as Health Economics intern and subsequently joined the Market Access & HEOR team at a Swiss dermatological company as Pricing Analyst. Her research interests are health economics modelling and health technology assessment, patient reported outcomes research, health policy.

DOCTORAL PROGRAM

Chair of Health Care Management, School of Medicine, University of St. Gallen, St. Gallen, Switzerland, Expected completion in 2024

SUPERVISORS (ROLES):

Alexander Geissler, Prof. (Chair Holder)
Justus Vogel, Dr. (Postdoc)
David Kuklinski, Dr. (Postdoc)

PHD ABSTRACT

A dashboard is a data-driven clinical decision support tool capable of querying multiple databases and providing a visual representation of key performance indicators in a single report. The use of PROMs in clinical dashboards supports the clinician's understanding of how treatments impact symptoms scores and it enables the identification of health-related quality of life (HRQoL) deterioration or improvement at an early stage. In the previous literature, mostly the benefit of using disease-specific PROMs in combination with clinical dashboards has been highlighted. In the context of this research area, the EQ-5D has only rarely been used. To fill this gap, this project aims to evaluate the success factors of the design principles concerning clinical dashboards including generic – i.e., the EQ-5D – and disease-specific PROMs. To evaluate differences in the clinical dashboards' requirements for specific disease areas, the investigation of the clinical dash-board's potential is focused on a one-time intervention (i.e., hip and knee arthroplasty) and the long-term management of a chronic disease (i.e., COPD). To investigate the research question, a literature review is conducted to shed on light on focus aspects for the subsequent expert interviews. The findings from the prior steps will be used for the development of prototypes, which finally will be discussed by focus groups. The contribution of this research project is threefold: first, the elaboration of the success factors of clinical dashboards based on a literature review and expert interviews; second, the inclusion of the EQ-5D in combination with disease-specific PROMs into the dashboard, with a design that enhances the clinician's understanding of the patient's health status; third, the development of prototypes for both the one-time intervention and the chronic disease case and their evaluation in the focus groups, which will form the basis for building and developing the future "real" clinical dashboards.

EUROQOL RESEARCH

301-SG: Crafting and elaborating the potential of clinical dashboards incorporating PROMs , Co-Principal Investigator

AREA OF INTEREST

Population & Health Systems, Health & Wellbeing

Jiabi Wen, MSc

jiabi@ualberta.ca (pronouns: she/her/hers), Canada

BIOSKETCH

Jiabi Wen is a Ph.D. student at the University of Alberta and a research trainee at the Alberta PROMs and EQ-5D Research and Support Unit (APERSU). She obtained her MSc degree in Health Policy Research at the University of Alberta in 2020 and her BSc (Math) and BEcon (Economics) degrees from the Renmin University of China in 2018. Her research interests include economic evaluation and quality of life measures, particularly EQ-5D. Her Master's thesis focused on mapping for the EQ-5D-5L. In her Ph.D. studies, she is working on her thesis on the economic evaluation of wastewater surveillance. She is also involved in several
EQ-5D-related projects at APERSU, including the validation of the EQ-5D-Y-5L among children with juvenile idiopathic arthritis.

DOCTORAL PROGRAM

Health Services and Policy Research, School of Public Health, University of Alberta, Alberta, Canada, Expected completion in 2024

SUPERVISORS (ROLES):

Arto Ohinmaa, PhD (Supervisor)
Jeffrey A. Johnson, PhD (Co-supervisor)

PHD ABSTRACT

Background Juvenile idiopathic arthritis (JIA) is the most common type of arthritis among children, and it can cause permanent physical damage to joints, affecting mobility, pain and daily activities. The 3-level self-reported version of EQ-5D-Y has been validated in patients with JIA, but the validity of the 5-level version remains unknown.

Objectives Our first aim is to examine the performance of the EQ-5D-Y-5L parent-proxy version among children with JIA in terms of construct validity and informativity. Our second aim is to evaluate the responsiveness of the EQ-5D-Y-5L, and in particular, its ability to capture important effects of pain and function levels experienced by children with JIA.

Proposed methods We will use data from the UCAN CAN-DU (Canada-Netherlands Personalized Medicine Network in Childhood Arthritis and Rheumatic Disease) study cohort, which includes patients with new-onset JIA, those starting or stopping biologics, and patients with hard-to-treat JIA. Patients in this cohort have a baseline visit and a follow-up visit (either six-month or twelve-month). Demographics, clinical outcomes, medical history, the parent-proxy version of the childhood health assessment questionnaire (CHAQ), the parent-proxy version of the EQ-5D-Y-5L, and the global rating of change scale (only at follow-up visits) are collected. We will use data from the baseline visit to examine the construct validity and informativity and data from both the baseline and follow-up visits to examine the responsiveness.

Future research or innovations This validation study will help establish the validity of EQ-5D-Y-5L among children with JIA, providing evidence that the EQ-5D-Y-5L is appropriate for use among younger populations. This study will ultimately inform research that measures the quality of life impact of JIA and identifies treatments that improve the quality of life of these children.

EUROQOL RESEARCH

- Wen, J., Jin, X., Al Sayah, F. et al. Mapping the Edmonton Symptom Assessment System-Revised: Renal to the EQ-5D-5L in patients with chronic kidney disease. Qual Life Res 31, 567–577 (2022). https://doi.org/10.1007/s11136-021-02948-5
- Wen, J., Al Sayah, F., Simon, R. et al. Self-reported health-related quality of life of the general population in Alberta, Canada during the COVID-19 pandemic. J Patient Rep Outcomes 6, 109 (2022). https://doi.org/10.1186/s41687-022-00518-y

AREA OF INTEREST

Population & Health Systems, Younger Populations

Ava Fee Helena Hoogenboom, BSc (Network Leadership Team Member)

hoogenboom@eshpm.eur.nl (pronouns: she/her/hers), Netherlands

BIOSKETCH

After obtaining my BSc in Health Sciences, I moved on to be a MSc student in European Health Economics and Management with a specialization in Economic Evaluation. This master's program brought me to the University of Bologna, the Erasmus University of Rotterdam and the University of Oslo. I am currently a doctoral student at the Health Economics department of Erasmus School of Health Policy and Management (ESHPM) at Erasmus University Rotterdam.

DOCTORAL PROGRAM

Health Economics, Erasmus School of Health Policy and Management, Erasmus University Rotterdam, Netherlands, Expected completion in 2027

SUPERVISORS (ROLES):

Werner Brouwer, PhD (Supervisor)
Vivian Reckers-Droog, PhD (Co-supervisor)
Stefan Lipman, PhD (Co-supervisor)

PHD ABSTRACT

The aim of my PhD project is to examine the desirability, feasibility, and impact of involving children in the valuation of EQ-5D-Y health states. We will explore the theoretical/normative and empirical underpinning of involving stakeholders, in particular children, in decisions in health and healthcare. Furthermore, the project will focus on whether and why child and adult members of the public, and policymakers in healthcare believe that involving children in the valuation of EQ-5D-Y health states would be desirable and feasible. Research will be conducted on the various ways in which children can potentially be involved in the valuation of EQ-5D-Y health states and the impact of such involvement on the value of health states.

EUROQOL RESEARCH

1462-PHD Involving children in the valuation of EQ-5D-Y health states

AREA OF INTEREST

Descriptive Systems, Valuation, Younger Populations, Health & Wellbeing

Zhongyu (Winston) Lang, MSc

76155lzh@eur.nl (pronouns: he/him/his), Netherlands

BIOSKETCH

My name is (Winston) Zhongyu Lang, a third-year Ph.D. student at Erasmus University Rotterdam. Prior to pursuing my Ph.D., I had a background in pharmacy and public health. As for work experience, I interned in the marketing departments of both Johnson & Johnson and Pfizer. My current research interest is the utility gap between the child perspective and the adult perspective during health state valuation.

DOCTORAL PROGRAM

Health Economics, Erasmus School of Health Policy and Management, Erasmus University Rotterdam, Zuid Holland, Netherlands, Expected completion in 2024

SUPERVISORS (ROLES):

Arthur Attema, Werner Brouwer

PHD ABSTRACT

Composite time trade-off (cTTO) utilities have been found to be higher when adults value health states for children than for themselves. It is not clear if these differences reflect adults assigning truly higher utilities to the same health state in different perspectives, or if they are caused by other factors, which are not accounted for in the valuation procedure. One research has been granted by EuroQol, which aims to test if the difference between children's and adults' cTTO valuations changes if a longer duration than the standard 10 years is used. We intend to conduct personal interviews with a representative sample of 150 adults in the UK were conducted. We employ the cTTO method to estimate utilities of four different health states, where adults consider states both from their own and a 10-year-old child's perspective, for durations of 10 and 20 years. We also correct the cTTO valuations for perspective-specific time preferences in a separate task, again for both perspectives.

EUROQOL RESEARCH

- EQ Project 236-2020RA: QALYs or equity weights? The influence of differences between health state utilities for children and adults on priority setting. Second author
- EQ Project 237-RA: The effect of duration and time preference on the gap between adult and child health state valuations in time trade-off. First author

AREA OF INTEREST

Descriptive Systems, Valuation, Younger Populations

Liisa Maija Penttinen, MSc

liisa.penttinen@thl.fi (pronouns: she/her/hers), Finland

BIOSKETCH

My academic background is in Health Sciences. I have a master's degree in Science (Health Care) from the University of Eastern Finland, UEF (2017) and a bachelor's degree in physical therapy (2004). Since 2017, I have been working for the Finnish Institute for Health and Welfare (THL). I work as a Senior Planning Officer and my work includes coordinating a national TOIMIA network that updates all the information on our TOIMIA functioning measures database.. I'm also coordinating the process of defining one generic patient-reported outcome measure (PROM) for Finnish National Quality Registers. My research interests include especially different generic PROMs in assessing the effectiveness of health care interventions; what are the pros and cons of different generic PROMs? I also have interest in measurement properties i.e. psychometrics of the measurement instruments.

DOCTORAL PROGRAM

Faculty of Health Sciences, Institute of Clinical Medicine, University of Eastern Finland (UEF), Kuopio, Finland, Expected completion in 2027

SUPERVISORS (ROLES):

Janne Martikainen, PhD (Professor)
Paulus Torkki, PhD (Associate Professor)

PHD ABSTRACT

The tightening financial situation in Finland's health and social care sector, as well as the need of the professionals, are constantly hot topics in the speeches of decision-makers and in the general media. We are faced with an inevitable question: if the money and staff are not enough for everything, how do we choose the interventions for which the resources are used? The information collected by the quality of life (QoL) instrument alone cannot be used as a basis for prioritization, but it offers one more tool in the toolbox that aims to improve the quality and effectiveness of healthcare interventions. In Finland, many generic PROMs are being used and no national, uniform policy has been made. Certain QoL measures (i.e. generic PROMs) enable the calculation of quality-adjusted life years and provide us with information on how the intervention is reflected in the patient's or client's QoL. Disease-specific instruments capture usually more in-depth information on patient's symptoms or health issues yet generic instruments allow comparisons between patient groups and thus are often preferred in health economics. In this dissertation, the differences and similarities of certain generic PROMs are examined, and the new Finnish population reference values for one of the most used generic PROMs are drawn up. Research articles 1. Finnish Population Reference Values for EQ-5D-5L using Danish Value set 2. The differences and similarities between different generic PROM tools; EQ-5D-5L, PROMIS Global Health and Overall Well-being – how do certain health states or individual's lifestyle reflect to absence from work due to a health problem? 3. Does the QoL differ between people with or without disabilities? Which underlying factors affect individual's QoL the most (EQ-5D-5L and EuroHIS-8)? 4. New Finnish Value Set for EQ-5D-5L (tentative)

EUROQOL RESEARCH

-

AREA OF INTEREST

Population & Health Systems, Health & Wellbeing

Lilla Roy, MSc, BScN, RN

lroy@ualberta.ca (pronouns: she/her/hers), Canada

BIOSKETCH

My name is Lilla. I am of mixed settler ancestry from Mi'kma'ki (Nova Scotia, Canada) and now live and work in Treaty 6 territory (Edmonton, Canada) as a PhD candidate in the School of Public Health (Health Services & Policy Research, University of Alberta). I studied nursing (Laurentian University, 2008) and have experience in emergency and general nursing in urban, rural, and remote contexts. I completed a Master of Science (University of British Columbia, 2013) and worked as a research assistant before returning to clinical nursing (2015) and nurse education (2017). My research experience is increasingly community-based and relationally focused on health needs of underserved populations. In my PhD, as a non-Indigenous person, I wish to contribute to the decolonization of current health systems exploring how current (western-derived) measures, such as the EQ-5D, relate to Indigenous worldview and to what degree they measure health for Indigenous people.

DOCTORAL PROGRAM

School of Public Health, University of Alberta, Alberta, Canada, Expected completion in 2024

SUPERVISORS (ROLES):

Jeff Johnson, PhD (Supervisor)
Fatima Al Sayah, PhD (Committee Member)
Susan Chatwood, PhD (Committee Member)

PHD ABSTRACT

Background. In many countries, there are calls to address health inequalities experienced by Indigenous people. Indirect generic preference-based measures (PBMs) of health-related quality of life (HRQL), such as the EQ-5D, provide a measurement of individuals' or populations' health and can support resource allocation decisions. However, the usefulness of any PBM is partially contingent on the appropriateness of the measure for the population in which it is used. Indigenous people conceptualize health differently than traditional biomedical models of health, so it is important to assess validity and reliability of PBMs in Indigenous populations.

Objectives. 1) systematically examine the use of PBM in Indigenous people, 2) explore face and content validity of the EQ-5D-5L and interpretation of traditional choice-based health valuation tasks for Indigenous people, and 3) examine stated preferences for attributes of health based on the EQ-5D-5L descriptive system and compare how preferences differ from non-Indigenous people.

Proposed Methods. I propose mixed methods, informed by a systematic review on the application, development, and performance of PBM in Indigenous people. We will engage Indigenous people as respected members of the study team. Face and content validity of the EQ-5D-5L and interpretation of traditional stated choice and health valuation tasks will be explored using a qualitative and think-aloud approach, followed by exploration of stated preferences to explore differences between Indigenous and non-Indigenous people.

EUROQOL RESEARCH

216-2020RA: Exploring validity of the EQ-5D-5L for Indigenous people of Canada, Co-applicant (PhD student)

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems

Maikhone Vilakhamxay

maikhone@yahoo.com (pronouns: he/him/his), Lao PDR

BIOSKETCH

I have a bachelor's degree majoring in pharmaceutical sciences from the Faculty of Pharmacy, University of Health Sciences Lao PDR, and a master's degree in Advanced Drug Delivery Systems from Tianjin University of Traditional Chinese Medicine China. Before commencing my Ph.D., I have been working as a junior lecturer for the Faculty of Pharmacy, University of Health Sciences Lao PDR. Therefore, my Ph.D. research focuses on "Validating two Health-Related Quality-of-Life instruments for use in health technology assessment of interventions for stunted children in Laos"

DOCTORAL PROGRAM

The Faculty of Pharmacy, Social and Administrative Pharmacy, Silpakhorn University, Nakhorn Patom, Kingdom of Thailand, Expected completion in 2025

SUPERVISORS (ROLES):

Nan Luo, Main Thesis Advisor
Mayfong Mayxay, Co-Investigator
Elizabeth Ashley, Co-Investigator
Yot Teerawattananon, Co-Investigator
Sanyalack Saysanasongkham, Collaborator
Michael Herdman, Collaborator

PHD ABSTRACT

The project aims to develop the EuroQol Group’s child-friendly EQ-5D (EQ-5D-Y) and Toddler and Infant Population Scale (EQ-TIPS), two generic health-related quality of life (HRQoL) instruments, for use in stunted children in Laos. The overall aim is to localize the two instruments for assessment of the health burden related to stunting in Laos. The specific objectives are: 1. To develop a Lao version of the EQ-5D-Y questionnaire for use by proxies; 2. To assess the content validity of EQ-5D-Y and EQ-TIPS for measuring the HRQoL of Lao children under the age of 5; 3. To investigate construct validity and test-retest reliability of EQ-5D-Y and EQ-TIPS among parents of stunted children under the age of 5.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems, Younger Populations, Health & Wellbeing

Jan Faller, M.Hecon (Network Leadership Team Member)

jan.faller@monash.edu (pronouns: he/him/his), Australia

BIOSKETCH

I am a PhD student and researcher with the Monash University Health Economics Group (MUHEG). My PhD is focused on the inclusion of carer outcomes (spillover) in health economic evaluations using the EQ-5D. I have a Masters degree in Health Economics and Bachelors degree in Nursing. I have contributed in several economic evaluation and programme evaluation projects in the area of mental health.

DOCTORAL PROGRAM

Monash University Health Economics Group, School of Public Health and Preventive Medicine, Monash University, Victoria, Australia, Expected completion in 2026

SUPERVISORS (ROLES):

Lidia Engel, PhD (Main Supervisor)
Cathy Mihalopoulos, PhD (Co-supervisor)
Gang Chen, PhD (Co-supervisor)
Brendan Mulhern, PhD (Co-supervisor)

PHD ABSTRACT

Economic evaluations have traditionally considered only the costs and benefits of the person receiving care; however, recent guidelines now support the inclusion of broader impacts in economic evaluations, such as informal carer costs and benefits when adopting a societal perspective. While carer-specific preference-based measures are available for capturing carer impacts, there is increased interest from HTA bodies (e.g. NICE) to use the EQ-5D, ensuring consistency across evaluations and the ability to combine patient QALYs and carer QALYs using the same outcome measure. Incorporating carer outcomes or 'spillover effects' into economic evaluation requires further investigation into the extent of potential 'double-counting'. Hence, there is an urgent need for further research to examine how carer QoL can be included in economic evaluations using the EQ-5D. The PhD's aim is to address current methodological issues concerning the inclusion of carer outcomes in economic evaluation using the EQ-5D tools. The research will address a series of inter-related but distinct questions: (1) What is the psychometric performance of the EQ-5D tools in capturing carer outcomes for use in economic evaluation? (2) What is the extent of double-counting when including carer outcomes in economic evaluation using the EQ-5D? (3) Should 'carer QALYs' be weighted differently than 'patient QALYs' in economic evaluation? A systematic review on the psychometric properties of the EQ-5D in informal carers will be conducted to understand its performance in the carer population and identify potential gaps. Further, a study will be conducted examining the psychometric properties of the EQ-5D-5L compared with carer-specific preference-based measures in informal carers in Australia. Lastly a mixed-methods study will be conducted to explore the extent of double-counting when including carer outcomes in economic evaluations, and whether 'carer QALYs' should be weighted differently than 'patient QALYs'.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems

Begashaw Melaku Gebresillassie, MPH, MSc, BPharm

begashawmelaku.gebresillassie@uon.edu.au (pronouns: he/him/his), Ethiopia

BIOSKETCH

I am Begashaw Melaku Gebresillassie, currently a PhD student at the University of Newcastle, NSW, Australia. I proudly earned my Master of Public Health (MPH) from The University of Manchester, UK, and hold MSc and Bachelor of Pharmacy degrees from the University of Gondar, Ethiopia. Previously, I served as an Assistant Professor of Clinical Pharmacy at the University of Gondar, Ethiopia, and was honoured as the President-elect at ISPOR Ethiopia. In these roles, I actively contributed to teaching undergrad and postgraduate students, conducted health research, and provided community services. My research interests encompass public health, pharmacy practice, health outcomes, medical decision-making, patient decision support interventions, and chronic disease management. As I pursue my PhD, I am committed to advancing knowledge in these areas, drawing on my academic journey and diverse experiences.

DOCTORAL PROGRAM

School of Medicine and Public Health, The University of Newcastle, NSW, Australia, Expected completion in 2026;

SUPERVISORS (ROLES):

Melissa Harris, PhD (Primary supervisor)
John Atia, PHD, MD (Co-supervisor)

PHD ABSTRACT

Background: Non-cancer chronic diseases present a significant global health challenge, necessitating a nuanced approach to mortality prediction and intervention. This project identified easily available and measurable variables, particularly those related to health service use and health-related quality of life (HRQoL), as crucial indicators capturing the complex and dynamic nature of non-cancer chronic diseases (NCDs). Recognizing the substantial associations between changes in health service use and HRQoL over time and mortality outcomes underscores the need for a more comprehensive predictive model.

Aims: The primary objective is to develop a robust predictive model for non-cancer chronic disease mortality by integrating diverse data sources. The incorporation of HRQoL measures may improves the precision of the model, leading to the development of a personalized risk stratification tool. This tool aims to facilitate the early identification of individuals at high risk, optimizing the timing of palliative care referral, and ultimately improving overall patient outcomes.

Methods: Interdisciplinary methodologies, comprising advanced statistical modeling, and data integration techniques, form the foundation of this project. Rigorous validation processes, including cross-validation and sensitivity analyses, will be employed to ensure the reliability and generalizability of the predictive model. The inclusion of HRQoL measures not only expands our understanding of individual risk profiles but also enhances the overall accuracy of the predictive model.

EUROQOL RESEARCH

- doi.org/10.1155/2023/1744472, doi.org/10.1007/s11136-023-03473-3
- 436-RA: Comparison of the psychometric properties of self-complete and proxy version of the EQ-5D-Y-3L in Ethiopian children with prevalent acute illnesses, Research grant, Principal investigator
- 1591-RA: Health-Related Quality of Life Measures in Africa, Research grant, Principal investigator

AREA OF INTEREST

Descriptive Systems, Population & Health Systems, Younger Populations, Health & Wellbeing

Peiwen Jiang, MS

peiwen.jiang-1@student.uts.edu (pronouns: she/her/hers), Australia

BIOSKETCH

Peiwen is a PhD candidate and health economist with the Centre for Health Economics Research and Evaluation at University of Technology of Sydney (UTS). Her research interests focus on health valuation, quality of life instruments and discrete choice experiment methodologies. Peiwen holds a Master's degree in Health Data Science from the University of New South Wales and a Bachelor's degree in Science (Mathematics)/Master of Nursing from the University of Sydney. She brings a blend of experience, having worked as a registered nurse in primary care and in data analysis roles in the tech sector.

DOCTORAL PROGRAM

Centre for Health Economics Research and Evaluation, Faculty of Health, University of technology Sydney, New South Wales, Australia , Expected completion in 2025

SUPERVISORS (ROLES):

Prof. Deborah Street, PhD (Primary supervisor)
A/Prof. Brendan Mulhern, PhD (Co-supervisor)
Prof. Rosalie Viney, PhD (Co-supervisor)

PHD ABSTRACT

Resources in health care are scarce. Economic evaluations are required to allocate resources efficiently in health. In the domain of CUA, the main outcome is defined as quality-adjusted life years (QALYs) and the estimation of QALYs involves assessing both the quality and quantitative of life. While health-related quality of life instruments have been commonly used to measure quality of life, it is important to consider broader aspects of health including social outcomes like dignity and social participation. My PhD is part of a larger project that aims to combine existing instruments such as EQ-5D-5L and ASCOT into a broader descriptive system. Specifically, my research focuses on the valuation of the combined instrument using discrete choice experiments. This will provide decision-makers with a more comprehensive tool incorporating both health and social outcomes to achieve more equitable allocation of scare health care resources.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation

Stevanus Pangestu, MBA (Network Vice Chair)

pangestu@atmajaya.ac.id (pronouns: he/him/his), Hungary

BIOSKETCH

Stevanus Pangestu is a PhD candidate in the Department of Health Policy at Corvinus University of Budapest, Hungary. His studies are fully funded by the Stipendium Hungaricum scholarship, and he is expected to graduate in 2025. He holds a BSc in Accounting and an MBA from Atma Jaya Catholic University of Indonesia. Stevanus's research focuses on measuring health-related quality of life and wellbeing in patients with cancer, with a particular emphasis on financial wellbeing.

DOCTORAL PROGRAM

Department of Health Policy, Corvinus University of Budapest, Budapest, Hungary (Expected Graduation: 2025)

SUPERVISORS (ROLES):

Professor Fanni Rencz, MD, PhD (Supervisor)

PHD ABSTRACT

Cancer is a major leading cause of death worldwide. It accounts for a large proportion of global disease burden in terms of disability-adjusted life-years. Patients with cancer generally experience the decline of health-related quality of life (HRQOL) and wellbeing. Further, the diagnosis and treatment of cancer may also lead to financial toxicity, which is the impairment of financial wellbeing in patients. The purpose of this project is to: i) perform a systematic literature review and meta-analysis on studies investigating the association of financial toxicity and HRQOL in patients with cancer, ii) validate the EQ-HWB in cancer and compare its measurement properties with other outcome measures, including EQ-5D-5L, and iii) investigate the associations between financial toxicity, HRQOL, and wellbeing. For the first aim, a systematic literature review and meta-analysis will be performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guideline using PubMed, Web of Science, CINAHL, and PsycInfo. For the second and third aims, a longitudinal study will be performed among patients with cancer in Indonesia. Outcome measures in the survey will include the EQ-5D-5L, EQ-HWB, Functional Assessment of Cancer Therapy-General from which FACT-8D utilities can be derived, Short Warwick-Edinburgh Mental Wellbeing Scale, and Comprehensive Score for Financial Toxicity. To assess the measurement properties of the health and wellbeing measures, floor and ceiling, item informativity, validity (convergent, known-group, test-retest), and responsiveness will be tested. This project will extend the literature on psychometric properties of EQ instruments, specifically within the patient group with cancer. The research will also reveal associations between financial toxicity and health and wellbeing outcomes in Indonesia.

EQ PAPERS (DOI)

10.1016/j.jval.2024.12.003

EUROQOL RESEARCH

- 1644-RA, Psychometric properties of the EQ-HWB in patients with breast cancer in Indonesia, Co-investigator
- 1700-RA, Cognition bolt-ons for the EQ-5D-5L and EQ- 5D-3L: a systematic review, Co-investigator
- 1800-RA, Social and temporal comparisons on the EQ-5D, Co-investigator
- 1883-RA, Qualitative bolt-on valuation, Principal investigator
- 1914-RA, Evaluating the psychometric properties of bolt-ons in breast cancer patients, Co-investigator
- 1910-RA, Qualitative study of the modified EQ-HWB in patients with breast cancer, Co-investigator
- 2003-RA, Adult vs child perspectives within respondents in cTTO valuations for EQ-5D-Y-3L, Principal investigator

AREA OF INTEREST

Descriptive Systems, Health & Wellbeing, Valuation

Daniel Youkee, MB BS MPH DTM&H

daniel.youkee@kcl.ac.uk (pronouns: he/him/his), Sierra Leone

BIOSKETCH

Dr Dan Youkee is an emergency medicine doctor and a PhD student at King's College London. Dan has lived and worked in Sierra Leone since 2014. His PhD focuses on the Impact of Stroke in Sierra Leone, supervised by Dr Iain Marshall and Prof Julia Fox-Rushby. As part of his PhD Dan led the translation of the Krio version of the EQ-5D-3L for Sierra Leone. Further work assesses the translation using an equivalence framework, assesses psychometric properties and reports utilities and quality-adjusted life years after stroke in Sierra Leone.

DOCTORAL PROGRAM

King's Global Health Partnerships, School of Population Health, King's College London, London/ Freetown, UK / Sierra Leone, Expected completion in 2024

SUPERVISORS (ROLES):

Iain Marshall, PhD MBBS (Lead supervisor), Julia Fox-Rushby, PhD (Second supervisor)

PHD ABSTRACT

86% of worldwide stroke mortality occurs in LMICs and is a targeted public health priority. However, evidence on the incidence and outcomes of stroke in low-income countries like Sierra Leone is limited. My PhD focuses on the impact of stroke in Sierra Leone, including mortality, functional outcome and health-related quality of life. The relevant parts of the thesis include the following three components: 1. Using an equivalence framework to translate and evaluate the EQ-5D-3L in Krio for Sierra Leone 2. The feasibility, reliability, validity and responsiveness of the EQ-5D-3L in Krio for stroke patients in Sierra Leone 3. Quality of Life and Quality adjusted Life years after stroke in Sierra Leone This work may help further define and update translation methods and processes. We trial new methods to assess the functional equivalence of the translated versions and reflect on the utility (or not) of additional methods used in the translation process.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems

Marius Lamberg Torjusen, MD

torjusen.marius@gmail.com

BIOSKETCH

I'm a medical doctor based in Oslo, Norway. Since obtaining my M.D. in 2017, I have spent two and a half years working clinically, mainly as a general practitioner. I've also been involved in organising research and forecasting related to the pandemic for the Norwegian Institute of Public Health, and with the logistics for the Norwegian EQ-5D-5L valuation study. My research interests focus on how institutions can make better choices when allocating public goods. This includes figuring out how to best measure health and well-being, and developing decision-making frameworks that are both morally relevant and practical to implement.

DOCTORAL PROGRAM

The Health Services Research Unit - HØKH, Akershus University Hospital, University of oslo, Lørenskog, Norway, Expected completion in 2025

SUPERVISORS (ROLES):

Mathias Barra, PhD (Main supervisor)
Kim Rand, PhD (Supervisor)
David GT Whitehurst, PhD (Supervisor)
Knut Stavem, MD PhD (Supervisor)

PHD ABSTRACT

In the pursuit of fair and publicly acceptable priority setting in healthcare, several countries go beyond a health-maximisation approach and afford extra weight to the worse-off in terms of health. However, methodologies used in current evidence supporting this approach have some issues. This is because previous preference eliciting studies are not sufficiently accommodating for heterogeneous health state evaluation or ensuring that health state values are represented on a cardinal scale. To address these methodological shortcomings, this PhD project aims to determine whether individuals shift from health-maximising to inequality-reducing strategies in priority setting discrete choice experiment tasks using EQ-5D-5L health states with individual-level valuations. We conducted one-on-one interviews with members of the general Norwegian population supported by a custom data collection app. Individual-level EQ-5D-5L health state valuations were obtained through time trade-off. Priority setting tasks were formulated as a discrete choice experiment. Each task was a choice between treating a group in a worse initial health state or achieving a greater health improvement by treating a group comparatively better off. The choice descriptions used different operationalisations for health: both health state value (non-temporal QALY-weights) and QALY-based operationalisations. The project will contribute to the field of priority setting in healthcare specifically, but results may also have implications for other branches of health economics, medical ethics, and moral psychology. The project also showcases how EuroQol instruments can inform health decisions in a novel way.

EUROQOL RESEARCH

1340-RA: Severity and EQ-5D (SEVQ), PhD student

AREA OF INTEREST

Descriptive Systems, Valuation, Health & Wellbeing

Yan Li

ly09396@163.com (pronouns: she/her/hers), China

BIOSKETCH

I'm a direct Ph.D. student at China Pharmaceutical University, majoring in Pharmaceutical Economics. I completed my undergraduate studies in Pharmaceutical Administration at the same university. My research centers on pharmaceutical economics and children's quality of life. The project I am working on now is an investigation on the general child population in China utilizing the EQ-5D-Y and CHU-9D instruments.

DOCTORAL PROGRAM

School of International Pharmaceutical Business, China Pharmaceutical University, Jiangsu, China, Expected completion in 2027

SUPERVISORS (ROLES):

Pingyu Chen, PhD (Primary supervisor)
Xuejing Jin, PhD (Co-supervisor)
Tiantian Tao, PhD (Co-supervisor)

PHD ABSTRACT

Self-report is generally considered superior to proxy-report for assessing health utility wherever validly possible; however, self-assessment of health utility poses challenges in pediatric populations due to the lower age of children and limitations in cognitive capability and reading level. To address these challenges, proxy mechanisms have been developed and adopted by researchers, involving parents, caregivers, or physicians as proxies to measure and report children's health utility. Nevertheless, there has been ongoing controversy regarding whether proxy-reported assessments of children's health utility accurately reflect their actual health levels and the agreement between children's self-reports and proxy-reports. This study investigated a general Chinese child population aged 7-8 years with the EQ-5D-Y and CHU-9D to examine the agreement between self-reports and proxy-reports across various dimensions and overall health utility values, as well as to explore potential factors that may affect the agreement and health utility values. The aim is to provide valuable insights and references for the development of guidelines for self-reports and proxy-reports of children's health utility instruments and for economic evaluations in relevant pediatric populations.

EUROQOL RESEARCH

-

AREA OF INTEREST

Younger Populations

Ivan Chi Ho Au, BSc

auchiho@hku.hk (pronouns: he/him/his), Hong Kong SAR

BIOSKETCH

Ivan Au is a PhD candidate at the School of Public Health, The University of Hong Kong (HKU). He holds a Bachelor of Science degree from HKU, with majors in mathematics and risk management. His research interests include pharmacoepidemiology and biostatistics, effectiveness of antivirals and vaccinations for infectious diseases, health-related quality of life instruments, and cost-effectiveness of infectious disease interventions.

DOCTORAL PROGRAM

School of Public Health, University of Hong Kong, Hong Kong, Hong Kong SAR, Expected completion in 2025

SUPERVISORS (ROLES):

Carlos Wong, PhD (Supervisor)

PHD ABSTRACT

Effectiveness of nirmatrelvir/ritonavir in patients with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection: target trial emulation Currently there is a lack of population-wide evidence on the effectiveness of oral antiviral treatments for SARS-CoV-2 infection. This project aims to address this gap by evaluating the effectiveness of nirmatrelvir/ritonavir in different patient groups during the Omicron pandemic wave in Hong Kong. Several territory-wide, retrospective target trial emulation studies are conducted using the clone-censor-weight method. Study 1 included pregnant women with symptomatic omicron infection (DOI: 10.1038/s41591-023-02674-0). Study 2 includes children and adolescents aged 12-17 years with omicron infection. Studies 3 and 4 include non-hospitalized and hospitalized adult patients with omicron infection, respectively. Primary outcomes include all-cause mortality, hospitalization, in-hospital disease progression, maternal morbidity and mortality index (study 1), and multisystem inflammatory syndrome in children (study 2). Summary of presentations in previous EuroQol meetings Previous studies focused on the valuation and application of EQ-5D-Y in Hong Kong. Study 1 aimed to obtain preferences for EQ-5D-Y health states in the Hong Kong population, and investigate how preferences differed between adults' own perspective and the hypothetical 10-year-old child perspective during valuation. Study 2 assessed differences in EQ-5D-Y health problems, utility scores (estimated using the published Chinese EQ-5D-Y value set), and EQ VAS scores across age and gender groups of school-attending children and adolescents in Hong Kong. Study 3 assessed associations between EQ-5D-Y-5L responses, EQ VAS scores, and responses and summary scores on the PedsQL instrument among children and adolescents in Hong Kong. This study also explored the feasibility of mapping EQ-5D-Y-5L responses from PedsQL scores.

EUROQOL RESEARCH

-

AREA OF INTEREST

Valuation, Younger Populations

Kinza Degerlund-Maldi, MSc

kinza.degerlund.maldi.2@ki.se (pronouns: she/her/hers), Sweden

BIOSKETCH

My name is Kinza Degerlund-Maldi, and I started a PhD at Karolinska Institutet in Sweden in September 2023. Alongside doing my PhD I am also working as a health economist at Stockholm Center for Health Economics at Region Stockholm. I have a MSc in Public Health with a Specialization in Health Economics from Umeå University, Sweden, and a BSc in Nursing with Registration as a Mental Health Nurse from King's College London, England. I have also worked clinically as a nurse in England. In my PhD, I am studying health economic aspects related to the follow-up of patients with rheumatic disease, with a focus on the use of EQ-5D-3L and EQ-5D-5L. My research interests are in how to measure and value health using instruments such as EQ-5D.

DOCTORAL PROGRAM

Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Stockholm, Sweden, Expected completion in 2028

SUPERVISORS (ROLES):

Emelie Heintz, Associate professor (Main supervisor)
Malin Regardt, PhD (Co-supervisor)
Camilla Nystrand, PhD (Co-supervisor)
Ioannis Parodis, Associate professor (Co-supervisor)

PHD ABSTRACT

Background: The Swedish Rheumatology Quality Register (SRQ) is a national quality register, aimed at improving the treatment and follow-up for patients with rheumatic disease, such as rheumatoid arthritis (RA), psoriatic arthritis, polyarthritis, and ankylosing spondylitis. The register started collecting data with EQ-5D-3L in 2008, and in 2018 the register contained approximately 300 000 EQ-5D measurements. EQ-5D-3L is usually collected in relation to follow-up visits. According to national guidelines, patients with RA should have regular follow-up visits, either face-to-face or digitally. During the Covid-19 pandemic, digital visits (telephone and video) partly or fully countered the decrease in face-to-face visits. Aim and method: The first objective is to assess the construct validity and responsiveness of EQ-5D-3L in patients with rheumatic disease in Sweden. This evaluation will be based on registry data from the SRQ. The second objective is to evaluate and compare the construct validity and responsiveness of EQ-5D-3L and EQ-5D-5L in patients with rheumatic disease in Sweden. This will be done based on an ongoing data collection where patients are randomized to answer either EQ-5D-3L or EQ-5D-5L first. The construct validity and responsiveness will be assessed by evaluating hypotheses about the relationship between EQ-5D, and other instruments. The last objective is to explore the impact of type of follow-up visit on HRQoL, measured with EQ-5D-3L, clinical outcomes, and health care utilization in patients with RA, and to identify whether there are socioeconomic differences. This will be done by linking national and regional registries. The results regarding the construct validity and responsiveness of EQ-5D-3L and EQ-5D-5L will be used to inform future decisions about which instrument to use for the follow-up of patients with rheumatic disease. Additionally, the study on type of follow-up visit will guide clinicians in determining whether digital visits can effectively replace face-to-face visits.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation

Jan Manuel Heijdra Suasnabar, MSc

j.m.heijdra_suasnabar@lumc.nl (pronouns: he/him/his), Netherlands

BIOSKETCH

I completed my MSc in Public Health for Development at the London School of Hygiene and Tropical Medicine. Prior to that, I was a research project officer at the Netherlands Institute for Mental Health and Wellbeing (Trimbos Institute) and completed my BSc in Psychology. I initially joined the Leiden University Medical Center (LUMC) as a junior researcher and now went on to pursue a PhD. My research interests include the broader measurement of quality of life (QoL), methodological challenges in economic evaluations, and international development.

DOCTORAL PROGRAM

Biomedical Data Science, Leiden University Medical Center, Leiden, the Netherlands, Expected completion in 2025-2026

SUPERVISORS (ROLES):

Ewout Steyerberg, PhD (primary supervisor)
Elske van den Akker-van Marle, PhD (co-supervisor)
Wilbert van den Hout, PhD (co-supervisor)

PHD ABSTRACT

My PhD project comprises a diverse set of studies related to health economics, with a focus on methodological aspects. Several studies are economic evaluations of surgical interventions, screening interventions, and digital health interventions. More relevant to EuroQol, my PhD includes two studies on the (broader) measurement of quality of life: 1. Exploring the Measurement of Health-related Quality of Life and Broader Instruments: This EuroQol-funded project uses exploratory/confirmatory factor analyses and qualitative methods to investigate the evaluative space of existing health and wellbeing instruments, with the aim of informing the development of future broad QoL measures. 2. Applying Large Language Models to Identify EQ-5D Bolt-ons Based on Patient Text Data: a EuroQol-funded seed grant, this innovative project explores the applicability/potential of large language models (such as GPT-4) for identifying relevant EQ-5D bolt-ons that may be useful in routine clinical practice settings. Findings from this project would be relevant to inform EuroQol's future guidelines for the identification/development of bolt-ons, and could inform future research on the potential advantages and challenges of artificial intelligence in the field of outcomes research.

EUROQOL RESEARCH

- 10.1016/j.socscimed.2024.116720
- 1447-RA: Investigating the dimensionality of wellbeing instruments and their added value in explaining health and wellbeing, Analyst
- 1792-SG: Applying Large Language Models to Identify EQ-5D Bolt-ons Based on Patient Text Data, Analyst

AREA OF INTEREST

Descriptive Systems, Population & Health Systems, Health & Wellbeing

Aysenur Ahsen, MSc

aysenur.ahsen@ese.eur.nl (pronouns: she/her/hers), Netherlands

BIOSKETCH

Aysenur Ahsen is a PhD candidate at Erasmus University Rotterdam in the Department of Applied Economics. Her research interests center around applied microeconomics, with a particular focus on health economics and gender economics. She holds a Bachelor's and Master's degree in Economics from Middle East Technical University, Turkey. Prior to her PhD studies, Aysenur worked on several research projects examining the intersection of education and health, particularly exploring how education impacts women's health decisions and outcomes. Her current research is part of a EuroQol-funded project that aims to identify and correct reporting heterogeneity in EuroQol instruments. This research has the potential to improve the comparability of self-reported health data.

DOCTORAL PROGRAM

Applied Economics, Erasmus University Rotterdam, Rotterdam, Netherlands, Expected completion in 2028

SUPERVISORS (ROLES):

Teresa Marreiros Bago d'Uva, PhD (Co-Supervisor)
Owen O'Donnell, PhD (Supervisor)

PHD ABSTRACT

EuroQol instruments are commonly used to compare health outcomes across groups defined by disease, demographic, socioeconomic, and other characteristics. However, systematic differences in how these groups respond to the instruments—referred to as reporting heterogeneity (RH)—can bias these comparisons. For instance, socioeconomic health inequality may be underestimated if individuals from lower socioeconomic groups report their health more positively than is justified by their actual health status. These differences in reporting may, in part, stem from varying levels of health knowledge and beliefs. Therefore, this PhD project, as part of the EuroQol-funded project titled "Reporting Heterogeneity in Health Description and Valuation: Identification, Correction, and Sources," aims to investigate and correct biases caused by RH in EuroQol instruments, specifically EQ-5D and EQ VAS. This research employs vignette-based methods to adjust for RH and investigates how sociodemographic factors contribute to these biases. By developing new methodological tools and utilizing econometric models like HOPIT, the project aims to enhance the validity of health comparisons across different populations.

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems, Health & Wellbeing

Goitom Molalign Takele, MSc

goitommolalign49@gmail.com (pronouns: he/him/his), Ethiopia

BIOSKETCH

I have completed my BSc in Comprehensive Nursing from Mekelle University and My Masters degree MSc in Emergency Medicine and Critical Care Nursing from Addis Ababa University. I have been working as a lecturer at Mekelle University with the responsibilities of teaching, leading conducting research, and doing community service. My research interests include Health outcome research, HRQoL, Psychometric studies, Acute Care, and Pre-Hospital Care

DOCTORAL PROGRAM

Ngai Tahu Maori Health Research Unit, Division of Health Sciences, Otago, Dunedin, New Zealand, Expected completion in 2027, Health Sciences Unit, University of Otago, Dunedin, Otago, New Zealand, Expected completion in 2027

SUPERVISORS (ROLES):

Sarah Derrett, Prof. (PhD) (Primary Supervisor)
Trudy Sullivan, PhD (Co-supervisor)
Mimmi Astrom, PhD (Co-supervisor)
Ari Samaranayaka, PhD (Co-supervisor)

PHD ABSTRACT

As for the adult population, measuring the health status of children and adolescents is vital for describing and monitoring the health of a population, for public health research, and evaluation of treatments. In Ethiopia, where 24% of the population is aged 10-18 years, it is particularly important to have information about the health status of adolescents. Therefore, this PhD project aims to increase knowledge on measuring health among adolescents aged 12-17 years in Ethiopia using the EQ-5D-Y-3L and EQ-5D-Y-5L instruments. Mixed methods will be employed. First, a systematic scoping review will be undertaken to identify: the approaches (modes of administration), instruments used, and factors associated with child and adolescent HRQoL in Sub-Saharan Africa. Then, extensive analysis of the (n=5000) adolescents' HRQoL data will be undertaken. Other than the common income and employment status measures of socio-economic status (SES), a new method of adolescent SES classification adopted from Ghanaian researchers will be tested in Ethiopia from the collected data set. Third, adolescent population norms will be presented using both the Y-3L and Y-5L instruments and the performance of the instruments will be compared. Fourth, factors associated with the HRQoL of adolescents, as measured using Y-3L and Y-5L instruments, will be assessed. Finally, the HRQoL of adolescents living with Type 1 diabetes will be compared with the General population using mixed-method study will be conducted.

EUROQOL RESEARCH

- 227-2020 RA: Comparison of the Afaan-Oromo language version of the EQ-5D-Y-3L and the EQ-5D-Y-5L performance among children and adolescents in Ethiopia, PI
- 317-RA: Investigating the aspects of HRQoL covered by the descriptive system and the added value of the respiratory bolt-ons (EQ-5D-5L+R): breathing problem and limitations in physical activities due to shortness of breath among patients suffering from asthma in Ethiopia, PI
- 449-RA: Assessing the health of Ethiopian Adolescents using the EQ-5D-Y-3L: A cross-sectional study, PI
- EuroQol Project 20191010: Psychometric properties feasibility and usefulness of the extended EQ-5D-Y-5L in children with prevalent disease conditions in Ethiopia, Co-investigator
- 1735-RA: Exploring the content validity of EQ-5D-Y-3L and EQ-5D-Y-5L among children and adolescents with Type 1 Diabetes Mellitus in Ethiopia. A Qualitative study, PI

AREA OF INTEREST

Descriptive Systems, Population & Health Systems, Younger Populations

Lyn Xuan Tay, BPharm

taylx@student.usm.my (pronouns: he/him/his), Malaysia

BIOSKETCH

I am a PhD student from Universiti Sains Malaysia with the research area of Alzheimer's Disease. I graduated as Bachelor of Pharmacy from UCSI University Malaysia in 2022 and certified as a fully registered pharmacist in Malaysia in 2023. My research interests are economic evaluation and Quality of life.

DOCTORAL PROGRAM

Discipline of Social & Administrative Pharmacy, School of Pharmaceutical Sciences, Universiti Sains Malaysia, Penang, Malaysia, Expected completion in 2025

SUPERVISORS (ROLES):

Siew Chin Ong, PhD (Supervisor)

PHD ABSTRACT

Alzheimer's Disease (AD) emerged as a public health concern worldwide along with the phenomenon of population aging. Health related Quality of Life is one important aspect in economic evaluation to understand the humanistic outcome of AD. The study aims to determine the cost of illness in AD and determine the HRQoL of both patients and caregivers in Malaysia. In the objective of HRQoL, proxy-rated EQ5D indices are measured via caregivers' report after written informed consent. With that, this research is able to fill up the knowledge gap regarding the health utility index in patients with AD and identify potential factors affecting HRQoL in Malaysia. With the application of EQ5D in such a vulnerable group, such research may contribute as empirical evidence in decision making among healthcare stakeholders and evaluating new disease-modifying interventions in the future.

EUROQOL RESEARCH

-

AREA OF INTEREST

Population & Health Systems, Health & Wellbeing

Pratik Khanal, MPH

pratik.khanal@uib.no (pronouns: he/him/his), Nepal

BIOSKETCH

Pratik Khanal is a PhD candidate at the Bergen Centre for Ethics and Priority Setting in Health (BCEPS), University of Bergen, Norway. He has a MPH degree from Institute of Medicine, Tribhuvan University, Nepal. He has around nine years of work experience in the health system of Nepal. His research interests are in the areas of health financing, economic evaluation, and non-communicable diseases (NCDs).

DOCTORAL PROGRAM

Department of Global Public Health and Primary Care, University of Bergen, Bergen, Norway, Expected completion in 2026

SUPERVISORS (ROLES):

Krishna Kumar Aryal (Supervisor)
Shiva Raj Adhikari (Supervisor)
Biraj Man Karmacharya (Supervisor)
Kjell Arne Johansson (Group leader)

PHD ABSTRACT

Very little is known about the application of EQ-5D-5L among patients with cancer in a low-resource setting. This study aims to report health status and associated factors among patients currently receiving cancer treatment in Nepal. Study design: A cross-sectional survey among patients with cancer attending tertiary cancer hospitals in Nepal. The EQ-5D-5L will be used to describe health states, and the EQ-VAS will be used to evaluate overall health status. The five-digit health profile from EQ-5D-5L will be converted to a single health utility index using the Indian value set. Descriptive statistics will be used to compute mean (standard deviation, SD) for continuous variables, and frequency and percentages for categorical data. Non-parametric tests, namely Mann-Whitney U-test and Kruskal-Wallis tests, will be used for identifying the association between socio-demographic variables and the health utility index. Spearman rank correlation test will be used to observe relationships between health utility index and continuous variables. Relevance: Identify variation in the value of health by socio-demographic characteristics and inform interventions

EUROQOL RESEARCH

-

AREA OF INTEREST

Descriptive Systems, Valuation, Population & Health Systems, Health & Wellbeing

Andrea De Palma, MPH
depalma@eshpm.eur.nl (pronouns: he/him/his), The Netherlands

BIOSKETCH

I am a PhD student within the Health Economics department at the Erasmus University Rotterdam. My research focuses on the validation of several well-being measures, aiming to enhance the evaluation of technology and services in non-curative care settings. I have a strong background in Psychology, with a BSc in Psychology from the University of Glasgow, an MSc in Social Psychology from Utrecht University, and an Italian Master in Quantitative Psychology from the University of Padua. Before commencing my PhD, I worked as Outcome Researcher in the Patient-Reported Outcome team within ICON. My research interests lie in psychometric analyses and patient-reported outcome measures.

DOCTORAL PROGRAM

Health Economics, Erasmus School of Health Policy and Management, Erasmus University Rotterdam, South Holland, The Netherlands, Expected completion in 2028

SUPERVISORS (ROLES):

Elly Stolk, PhD (Promotor)
Aureliano Finch, PhD (Co-promotor)
Job van Exel, PhD (Co-promotor)

PHD ABSTRACT

Our project aims to validate a series of wellbeing (WB) measures for evaluation of technology and services in non-curative care. Currently, cost-utility analyses are conducted to evaluate the effectiveness of an intervention, using quality-adjusted life years generated by health utility instruments as the main outcome. While health utility instruments have been shown to capture changes in health, they are limited in their assessment as they mainly focus on physical dimensions. This may provide a distorted picture when evaluating interventions and may lead to biased resource allocation, as the assessment may fail to capture important changes experienced by individuals in other dimensions, such as one's mental health, social life or independence. Multiple WB measures have been developed to address this issue, however these are at different stage of development, have been tested in different contexts/populations and/or have different theoretical foundations or scope. Consequentially, using them to assess technologies may yield different conclusions about treatment benefits. This project aims to bridge this gap by providing evidence of the psychometric properties and variations across different instruments in various non-curative care contexts. The overall project will have two parts: the first part involves an online cross-sectional data collection survey in a large and varied sample (N=7000) from the US and the Netherlands, with a follow-up measurement in a subgroup (25%). Part two involves case studies aimed at WB improvements in Dutch non-curative care clinical settings. The data will be used to assess the psychometric performance and fit-for-purpose of these wellbeing measures. The study will be particularly relevant for the EuroQoL group given it will provide insights into some of the EuroQoL instruments, such as the EQ-5D-5L and EQ-HWB-S, and compare their performance to other WB measures (i.e., WiX, WOOP, ICECAP-A/O, SWB-5D, ASCOT-STC4, QOL-ACC).

EUROQOL RESEARCH

-

AREA OF INTEREST

Health & Wellbeing

APPENDIX

EuroQol PhD Network Code of Conduct

Version 2.0 - 01 January 2025

The *EuroQol PhD Network* is committed to providing a safe, inclusive, welcoming, and harassment-free experience for everyone. We try to cultivate a community with shared values, where people are comfortable exploring ideas, asking questions, and saying things like “I don’t understand” or “Why”. There are no stupid questions.

Be considerate in speech and actions. Actively seek to acknowledge and respect the boundaries of people who participate in our activities. Refrain from demeaning, discriminatory, or harassing behavior and speech. Assume competence in the people you interact with.

Take care of each other. Alert the chair and other leadership team members if you notice a dangerous situation, someone in distress, or a potential violation of this Code of Conduct, even if it seems inconsequential. We do not tolerate harassment in any form. In particular, we prioritize marginalized people’s safety over privileged people’s comfort.

This Code of Conduct applies to **all people** participating in the community, to **all modes** of interaction, and to **all events** hosted or endorsed. If anyone engages in harassing behavior, the co-chairs will take action that may include warning the offender or asking them to leave an event or an online channel either temporarily or permanently, or seeking help from law enforcement.

We welcome your feedback by email, and we thank you for working with us to make the *Network* a safe, enjoyable, friendly and enriching experience for everyone who participates.

The *EuroQol PhD Network Code of Conduct* has been influenced by discussion during the *EOWG PhD Roundtables* held in Summer 2022 and the rOpenSci Code of Conduct, which can be found at their website, https://ropensci.org/code-of-conduct/.