# torch

## TOOLS FOR OUTCOMES RESEARCH TO MEASURE & VALUE CHILD HEALTH

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## IN THIS ISSUE

## Welcome Message

Welcome to our first issue for 2023 of the 'Tools for Outcomes Research to Measure and Value Child Health' (TORCH) Newsletter.

As we are in the second half of the project, we reflect on our work thus far and look forward to what is still yet to come.

In this issue, the Research Spotlight is on Dr Martin Howell from The University of Sydney.

We hope you enjoy this issue of our TORCH newsletter.

Thank you for being a part of our community.

TORCH Research Team

# Researcher Spotlight

We are an international team of researchers and clinicians, from seven universities across Australia and the United Kingdom. In this issue we highlight one of our Chief Investigators, Dr Martin Howell from The University of Sydney.

**Dr Martin Howell**
The University of Sydney

Dr Martin Howell is a CI on the TORCH study, and part of the leadership team of Professor Emily Lancsar (ANU), Professor Kirsten Howard (Sydney), Professor Stavros Petrou (Oxford), and Dr Elisabeth Huynh (ANU).  Martin has made major contributions to the TORCH study as co-lead of three work packages and contributed to most other work packages.

Martin is a Senior Research Fellow in health economics at the Menzies Centre for Health Policy and Economics at the University of Sydney where he leads the 'Value Informed Decision Making' research stream. Since 2008 research interests have focused on applied health economics in the areas of assessment of preferences using discrete choice methods to address complex health research questions, patient reported outcome measures, and the conduct of trial based economic evaluations. Through this research he has developed a growing knowledge of the important differences in the values, preferences and priorities between patients, carers, the general community, health professionals and policy makers and how these are reflected (or not) in the provision of and access to health care. A key aspect of the TORCH study is to understand how the range of perspectives and values should or can be captured when assessing interventions and policies aimed at improving child health. There is no one perspective or viewpoint that should be thought of as being 'correct' or more important. This is always a prime challenge in providing health care that is efficient while addressing equity and community values.

In addition to TORCH, Martin is involved in a range of projects all of which have an underlying theme of providing effective and efficient health care or interventions that address the needs and priorities of patients and their families. He also has the privilege of working with many Aboriginal and Torres Strait Islander researchers in their pursuit of models of health care that meet the needs of their communities.

As a side note, this is Martin's 'second career'. Prior to 2008, Martin spent many years as a soil scientist with a keen interest in the environment and management of contaminated sites such as landfills and old paint factories.

# Project Update

As we are now comfortably into the second half of the TORCH project, we reflect on what we have achieved and what we are looking forward to completing.
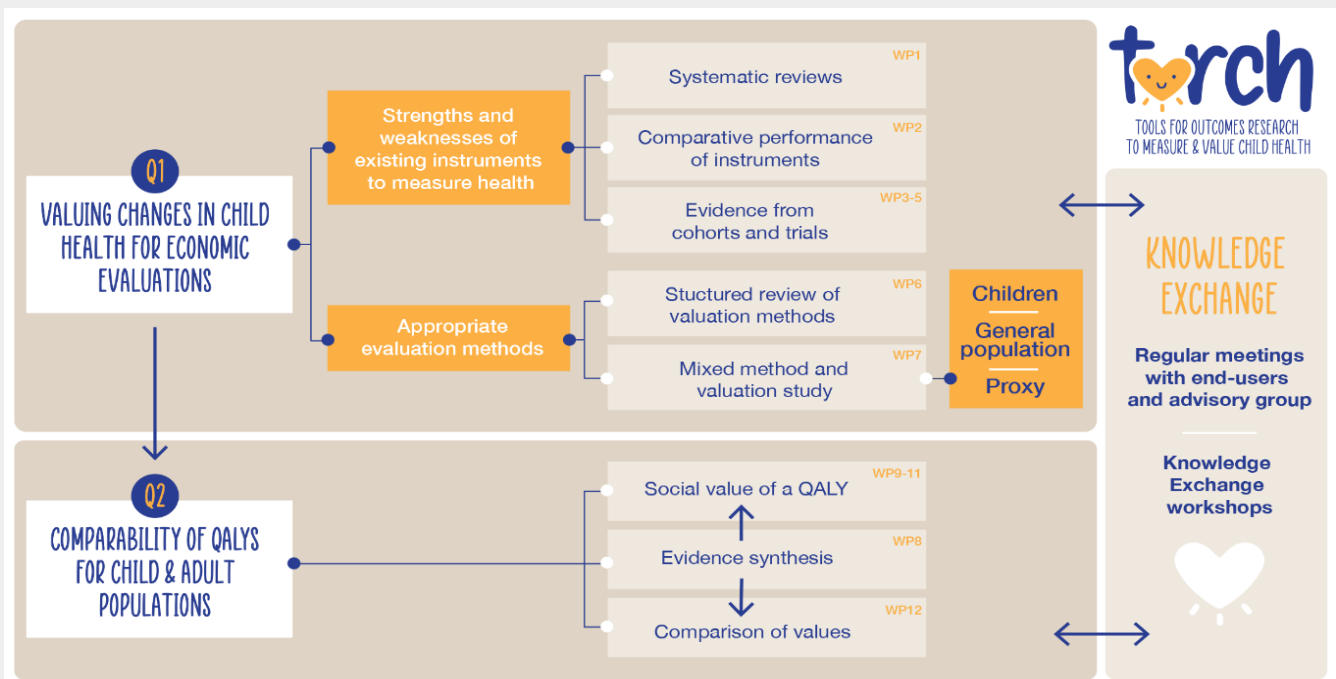
To recap, the TORCH study addresses two main overarching research questions:

(i) How to value changes in child health for economic evaluation?

(ii) How do Quality Adjusted Life Years (QALYs) for child populations compare with QALYs for adult populations?

The study involves meaningful collaboration between researchers, policymakers, clinicians, child health organisations, and young people to co-design the research. These collaborations ensure that research outcomes are fit-for-purpose and enable knowledge exchange between researchers and policymakers.

The diagram below summarises the work packages that address our two research questions.

The work packages (1-5) exploring the strengths and weaknesses of instruments to measure and value child quality of life have been completed. These drew on a portfolio of available data sources—including a unique database of published studies, ongoing clinical trials, and existing cohort studies—

complemented by the generation and analysis of qualitative and quantitative primary data. From this, TORCH published a number of papers including:

- Our first systematic review, `Systematic Review of Conceptual, Age, Measurement and Valuation Considerations for Generic Multidimensional Childhood and Patient Reported Outcome Measures' at PharmacoEconomics

- A second systematic review, 'Systematic Review of the Psychometric Performance of Generic Childhood Multi-attribute Utility Instruments' was more recently published in Applied Health Economics and Health Policy.

- 'Reliability, acceptability, validity and responsiveness of the CHU9D and PedsQL in the measurement of quality of life in children and adolescents with overweight and obesity' which was published at the International Journal of Obesity.

- 'Methodological challenges surrounding QALY estimation for paediatric economic evaluation' came out of work package 2 and was published at Cost Effectiveness and Resource Allocation.

- Lastly, 'Baseline characteristics of participants in the NAVKIDS trial: a patient navigator program in children with chronic kidney disease" was accepted last year in Pediatric Nephrology.

The other major stream of work that we are currently wrapping up focuses on social value of QALYs for children drawing on multiple sources of evidence including a systematic review of existing evidence in the literature regarding whether QALYs for children and young people are valued differently to adults; a qualitative study involving interviews with young people, adults, and participants in Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) Health Technology Assessment (HTA) processes which asked: are QALY gains in children of similar value to adults?; and a discrete choice experiment which focuses on eliciting preferences regarding prioritisation of children and young people compared to other age groups and other characteristics over which people may hold a social value.

Based on the evidence of the strengths and weaknesses of instruments to measure quality of life in children from work packages 1-5, the team, in consultation with our end user and advisory groups, selected the PedsQL as the child health related quality of life instrument to take forward into an empirical study in work package 7 to generate Australian value sets which can be used to generate QALYs for use in economic evaluation. We are also testing different methods to elicit such values sets in work package 7, informed by a recent TORCH publication on the 'Methodological challenges surrounding QALY estimation for paediatric economic evaluation' at BioMed Central and a systematic review of methods to value child quality of life.

The start to work packages 11 and 12 is imminent and we are excited to begin this work. We will share progress in these work packages in our next newsletter.

New publications and our presence at the upcoming International Health Economics Association (IHEA) Congress are outlined below.

While we reflect on the immense work undertaken

thus far, we do so acknowledging the collaborative process of a large, international team. We are proud to have achieved what we have to date drawing on solid communication and problem-solving skills within the team. It has been a pleasure working with and learning from each other and we look forward to the continued collaboration to meet our remaining research objectives.

# New Publications

Guha, C., Khalid, R., van Zwieten, A. et al. Baseline characteristics of participants in the NAVKIDS2 trial: a patient navigator program in children with chronic kidney disease. Pediatr Nephrol 38, 1577–1590 (2023).
DOI: 10.1007/s00467-022-05772-2
PDF: https://link.springer.com/article/10.1007/s00467-022-05772-2

Hayes A, Raghunandan R, Killedar A, Smith S, Cvejic E, Howell M, Petrou S, Lancsar E, Wong G, Craig J and Howard K. Reliability, acceptability, validity and responsiveness of the CHU9D and PedsQL in the measurement of quality of life in children and adolescents with overweight and obesity. Accepted International Journal of Obesity March 2023.
DOI: 10.1038/s41366-023-01305-5
PDF: https://www.nature.com/articles/s41366-023-01305-5.pdf

Kwon, J., Smith, S., Raghunandan, R. et al. Systematic Review of the Psychometric Performance of Generic Childhood Multi-attribute Utility Instruments. Appl Health Econ Health Policy (2023).
DOI: 10.1007/s40258-023-00806-8
PDF: https://link.springer.com/article/10.1007/s40258-023-00806-8

# Conferences

The following papers have been accepted for oral presentation at the iHEA Congress, this year held in Cape Town, South Africa July 8 - 12:

- 'Systematic Review of the Psychometric Performance of Generic Childhood Multi-Attribute Utility Instruments' (Stavros Petrou presenting)

- 'Values for Childhood Health-Related Quality-of-Life: A Checklist for Studies Reporting the Elicitation of Stated Preferences' (Stavros Petrou will be presenting on behalf of the joint TORCH-QUOKKA teams as part of an organised session entitled: 'Issues in the Measurement, Valuation and Reporting of

Child and Caregiver Health and Quality of Life')

- Systematic Review: Preference Elicitation Techniques for Valuing Children's Health-Related Quality-of-Life (Martin Howell presenting on behalf of the joint TORCH-QUOKKA teams)

- A systematic review of the evidence on the social value of a child health versus adult health (Martin Howell preseting on behalf of the joint TORCH-QUOKKA teams).

# Delphi Update

The primary aim of this research project is to determine views on what is considered to be important characteristics of questionnaires that measure health states in children and young people for use in health economic evaluation. The secondary aim is to compare and contrast the views of our stakeholder groups (decision makers, young people, parents and carers). The Delphi consensus method is a process used to arrive at a group opinion on a topic. We intend to use three rounds of surveys.

Round 1 of our DELPHI survey was successfully launched late last year. In Round 1 we gave everyone the opportunity to say what they thought were the most important characteristics. We will now compile a list of characteristics that will be included in Round 2 which will be released very soon. The second round will be open to the general public over the age of 15, decision makers and clinicians and we would greatly appreciate you participating and also sharing to your networks. You do not have to have completed round 1 to join round 2. Click here to participate in Round 2.

For every round you complete, you can opt in to go in the running to win an Apple iPad!

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