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Welcome Message

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

The TORCH study commenced in late 2020, after being awarded an Australian Government Medical Research Future Fund (MRFF) Targeted Health System and Community Organisation Research Grant to improving the measurement and valuation of child health to inform government decision making on public funding for medicines, medical services and procedures.

In the TORCH newsletter series, we will promote and share our research and highlight our research methodologies. The newsletter will also serve as a platform for you to learn more about the TORCH research team.

In this second issue, we look more closely at the findings of a systematic review, dive into specific work packages and highlight one of our team members, Mr Joseph Kwon.

We hope you enjoy this issue of our TORCH newsletter.

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 Mr. Joseph Kwon from the University of Oxford.



Mr Joseph Kwon
University of Oxford

Since January 2022, I have been working as a health economist at the Nuffield Department of Primary Care Health Sciences, University of Oxford. I am

currently working on two projects:

- (i) Tools to measure and value health change in children (TORCH); and
- (ii) Long covid multidisciplinary consortium: optimising treatments and services across the NHS (LOCOMOTION).

For TORCH, I am investigating the psychometric evidence around childhood health utility measures. These were identified by a previous review conducted for TORCH and published in *Pharmacoeconomics*.

Publications

Systematic Review of Conceptual, Age, Measurement and Valuation Considerations for Generic Multidimensional Childhood Patient-Reported Outcome Measures

Patient-reported outcome measures (PROMs) are widely used tools for assessing the health status, health-related quality of life (HRQoL) or quality of life (QoL) from the perspective of patients. Yet the use of PROMs in children presents methodological challenges compared to their use in adults. Childhood PROMs have to account for age-based developments in children's health and social settings, as well as their cognitive capacity to report on their own health. Another challenge concerns valuing children's reported health states so that the valued health utilities can inform decisions in allocating healthcare resources.

As part of TORCH, we conducted a systematic review of generic (i.e., not specific to certain diseases), multidimensional (i.e., the measure covers multiple dimensions of health or quality of life) childhood PROMs and value sets that accompany them. The review catalogued the 89 identified PROMs by their conceptual basis, specifically whether they simply report the child's health status or position in life, or they seek to capture the child's perception

For LOCOMOTION, I am building an economic model for evaluating alternative Long Covid care strategies.

I have recently submitted my thesis for PhD in Public Health, Economics and Decision Sciences at University of Sheffield, and am awaiting Viva. The thesis explores the methodological challenges around economic modelling of geriatric public health interventions, focusing on community-based falls prevention as a case study. Key challenges included incorporating non-health outcomes and societal intervention costs, accounting for capacity constraints, estimating the value of community asset involvement, and evaluating joint efficiency-equity impacts. A new economic model of falls prevention was developed to address these challenges, which will hopefully inform the current update of the national clinical guideline to falls prevention in the UK.

on the reported health status (e.g., how important the given status is to the child). Several methodological features were described and enumerated: e.g., the proportion of PROMs compatible with child's self-report by childhood age subgroups. The second part of the review focused on the methodological features of 21 identified value sets (for 14 PROMs), including their preference elicitation techniques and statistical features. Overall, the catalogues generated by this systematic review should assist researchers, practitioners and policymakers in selecting the most appropriate PROMs and accompanying value sets for application within childhood populations according to their conceptual basis, target age, design and needs of the end user, including cost-utility analyses.

Read and download the [publication](#).

Methodological challenges surrounding QALY estimation for paediatric economic evaluation

Cost-utility analysis remains the preferred form of economic evaluation for health technology assessment, pricing and reimbursement authorities in several countries. The results of cost-utility analyses are commonly expressed in terms of incremental cost per quality-adjusted life year (QALY) gained where the QALY combines length of life and health-related quality of life in a single metric. This commentary provides an overview of key methodological

challenges surrounding QALY estimation for paediatric economic evaluation. These challenges include issues surrounding the relevant attributes to incorporate into measurement instruments, appropriate respondents for the measurement and valuation tasks, perspectives adopted when completing valuation tasks, potential sources of bias in the description and valuation processes, and the paucity of psychometric evidence for existing measures. In addition, the commentary considers methodological challenges raised by research aimed at assessing whether a QALY gain by a child should be valued equally to a QALY gain by an adult.

Read and download the full [publication](#).

Research Updates

DELPHI STUDY

As part of the TORCH Knowledge Exchange program of work, the research team is currently conducting a Delphi consensus study to better understand our stakeholders' views on characteristics of childhood health-related quality of life instruments for use in economic evaluations. The study will commence shortly.

We are recruiting for this study! The study will involve three short online surveys, and for every survey completed, entry into a prize draw for an Apple iPad is automatic.

If interested in participating in this study, or you know someone who might be, please contact us at TORCH@anu.edu.au.

WORK PACKAGES 3 -5

The NAVKIDS trial has completed recruitment of 176 children with chronic kidney disease. Follow-up will complete in October 2022 with plan results of the primary outcomes to be published in June 2023.

We have also completed the first longitudinal analyses of the Kids with CKD study (KCAD), and found that kidney transplantation improved the quality of life of children on dialysis, with an increment of 0.05 per year, that is a gain of 0.2 points over 4 years. This is a significant improvement and has major policy implications. Children on dialysis should be prioritised for transplantation as this is the single most important intervention that will improve not only the survival but also the overall well-being of children suffering with kidney failure.

Preference Elicitation Techniques Used in Valuing Children's Health-Related Quality-of-Life: A Systematic Review

Valuing children's health states for use in economic evaluations is globally relevant and is of particular relevance in jurisdictions where a cost-utility analysis is the preferred form of analysis for decision making. Despite this, the challenges with valuing child health mean that there are many remaining questions for debate about the approach to elicitation of values. The aim of this paper was to identify and describe the methods used to value children's health states and the specific issues that arise in the use of these methods.

Read and download the [publication](#).

WORK PACKAGE 9

Are Quality Adjusted Life Year (QALY) gains in children of similar value to those in adults? A qualitative exploration with young people, adults and decision makers.

This study aimed to compare the views of diverse stakeholders about whether children's health gains should be valued as equivalent to gains for adults in formal decision processes regarding funding of health technologies; and to describe how decision-makers navigate these social values in practice, particularly in relation to funding of health technologies for children and young people (CYP) compared to adults.

We undertook a qualitative study involving individual in-depth, semi-structured interviews with young people (aged 15-17), adults, and participants in Pharmaceutical Benefits Advisory Committee (PBAC) and Medical Services Advisory Committee (MSAC) Health Technology Assessment (HTA) processes. Data collection is complete and data analysis is currently underway with several manuscripts planned for publication.

WORK PACKAGE 10

Social Value of Child QALY- Stated Preferences

A Discrete Choice Experiment survey has been developed to explore whether children and young people's health gains should be treated as equivalent to gains for adults has been programmed. The survey embeds avatar videos explaining the task and attributes. We are currently pre-testing the survey in face-to-face interviews.

TORCH Website

New Staff

Launch of our new website

We are excited to announce that our new [website](#) is live!

You can find out more about TORCH online and how you or someone you know might be able to participate. You can also read our published research, meet the team involved and learn how you or someone you know can get involved.

Don't forget to also follow us on Twitter [@TORCHstudy](#).



Ms Kim Grant
Research Manager

Kim Grant has recently joined the team as the Research Manager taking over the reins from Jolene Cox. Kim has been with The ANU in varying roles over the last 16 years. Please reach out to Kim for anything TORCH related.



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TOOLS FOR OUTCOMES RESEARCH
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