



IN THIS ISSUE

RESEARCHER
SPOTLIGHT

PUBLICATIONS

RESEARCH UPDATES

CONTACT US

Welcome Message

Welcome to the final issue for 2022 of the 'Tools for Outcomes Research to Measure and Value Child Health' (TORCH) Newsletter.

We have had an eventful year: numerous publications, many fruitful meetings, lots of engaging research and work.

In this issue, we highlight our lead Chief Investigator, Professor Emily Lancsar, update you on our new publication since our last issue as well as provide research updates. We also attended the 43rd annual Australian Health Economics Society (AHES) Conference in Brisbane in September and give an overview of our presentations there.

We hope you enjoy this issue of our TORCH newsletter and hope you have safe and happy end of year celebrations. Thank you for being a part of our community. We look forward to working with you all in 2023!

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 our lead CI, Professor Emily Lancsar from The Australian National University.



Professor Emily Lancsar
ANU

Professor Emily Lancsar is CIA on the TORCH study, working closely with the leadership team comprising Professor Kirsten Howard (Sydney), Professor Stavros Petrou (Oxford), Dr Elisabeth Huynh (ANU) and Dr Martin Howell (Sydney).

Emily is Head of the Department of Health Services Research and Policy, and from 2020-2022 served as Associate Dean (Policy and Practice) in the College of Health and Medicine at The ANU. She is an economist with particular interests in valuing life and health, understanding and modelling choice, preferences and behaviour of key decision makers in the health sector, priority setting, economic evaluation and policy analysis.

What's the best thing about the TORCH study?

There are a lot of great things about TORCH!

Undertaking research to improve how we measure

and value child health to inform how we fund healthcare for children - with the ultimate aim of improving children's health and wellbeing - is top of the list.

Working with a great team is also up there. And it's a big team! We have 10 Co-Investigators, some of whom I have worked with for a long time while this has been my first opportunity to collaborate with others. This core team is supported by a further 21 Associate Investigators, including fellow academics, policy makers, representatives from child health organisations and young people!

Methodologically TORCH brings together a number of my research interests – especially our focus on valuing life, quality of life and wellbeing and using discrete choice methods to do so.

What are you looking forward to most over the next 18 months of TORCH?

Now that we are wrapping up a number of our foundational work packages, I am looking forward to TORCH shifting gears to test the best ways in which to elicit preferences of children and young people, which in turn will inform how we go ahead and develop a value set for one of the child quality of life measures. Based on the evidence generated in our early work packages we will be developing a value set for the PedsQL.

Publications

Baseline characteristics of participants in the NAVKIDS2 trial: a patient navigator program in children with chronic kidney disease

Children with chronic kidney disease (CKD) require multidisciplinary care to meet their complex healthcare needs. Patient navigators are trained non-medical personnel who assist patients and caregivers to overcome barriers to accessing health services through care coordination. This trial aims to determine the effectiveness of a patient navigator program in children with CKD.

Read and download the [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 first round of the study was launched on October 17.

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

WORK PACKAGE 2

A manuscript has been drafted for submission for publication.

WORK PACKAGE 3

Data extraction of relevant variables from the Longitudinal Study of Australian Children (LSAC) and Child Health Checkpoint has been completed. Psychometric assessment of PedsQL and CHU9D instruments in children with overweight and obesity has been completed. These results were presented at the Australian Health Economics Conference and the manuscript has been submitted to International Journal of Obesity for publication.

Psychometric assessment of PedsQL and CHU9D in children with additional paediatrics conditions has been completed and manuscript for publication is currently under review with Pediatric Nephrology.

Psychometric assessment of PedsQL in children with selected chronic conditions over three age groups completed and manuscript for publication is underway.

Analysis of data from Kids with chronic disease (KCAD) cohort study is completed and manuscript has been accepted for publication in [Kidney International](#).

WORK PACKAGE 4

Designed comparison and added instruments to the Neurodevelopment Australia longitudinal study. The initial analysis is in progress.

WORK PACKAGE 7

Work Package 7 is now in its planning stage with a view to begin work in January 2023.

WORK PACKAGE 8

A manuscript has been drafted for submission.

WORK PACKAGE 9

The first manuscript has been drafted for submission. This aims to describe the evaluative process used to make recommendations to subsidise new drugs and medical technologies in Australia, from the perspectives of those currently or previously involved in these processes. This manuscript was also accepted for an oral presentation at the Australian Health Economics Society conference in September 2022.

Write-up for the second manuscript is currently in progress. An abstract for this broader analysis was accepted for an oral presentation at the Health Services Research conference which will take place in December 2022.

WORK PACKAGE 10

Face-to-face pre-test interviews are now complete. Pilot data collection commenced in October.

WORK PACKAGE 11

A selection of public summary documents has been collected to examine whether data is sufficient to enable data extraction.

AHES CONFERENCE

The TORCH team were well represented at the Australian Health Economics Society (AHES) Conference which took place in September in Brisbane.

Professor Emily Lancsar presented a joint QUOKKA paper stemming from work package 6 titled "Values for child health related quality of life: a checklist of studies reporting the elicitation of stated preferences".

Dr Marcus Sellars presented a paper from research done in work package 9 titled "Making recommendations to subsidise new health technologies in Australia: a qualitative study of decision-makers' perspectives on committee processes". The objectives of which were: the health technology assessment (HTA)

processes for new drugs and novel medical technologies in Australia have been the focus of attention for possible reform. We aimed to describe the evaluative process used to make recommendations to subsidise new drugs and medical technologies in Australia, from the perspectives of those currently or previously involved in these processes.

The TORCH team also worked on a joint QUOKKA paper that was presented by Dr Tessa Peasgood from The University of Melbourne. The paper was titled "A systematic review of the evidence on the social value of a child health versus adult health".

Our research team were also involved in other presentations from outside the TORCH study.



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TOOLS FOR OUTCOMES RESEARCH
TO MEASURE & VALUE CHILD HEALTH

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