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## Welcome message

Welcome to the first 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 first issue, we provide an overview of the aims and objectives of the TORCH study and our planned work packages.

We hope you enjoy the first issue of our TORCH news-letter.

# **Study overview**

How do you put a price on child health?

The measurement and valuation of child health is a complex issue, often faced with practical and methodological challenges with child populations.

In many countries, health technology assessment agencies are tasked with making recommendations to governments on which medicines and health services should be publically funded. In Australia, the recommendations must consider the safety, effectiveness, and cost-effectiveness of the medicine/health technology, compared to alternative treatment. This includes comparing the costs and benefits of different medicines, where benefits are often measured in terms of improvements in length of life and quality of life, captured in the metric of 'Quality Adjusted Life Years' (QALYs).

Methods involved in the measurement and evaluation of quality of life have been designed predominantly for adults, but they may not be appropriate for children. Policymakers identified the need to develop and refine methods to measure and value child health, and then to use those methods to generate empirical values to inform policy. The TORCH study will address two broad questions:

(i) how to value changes in child health for economic evaluation; and

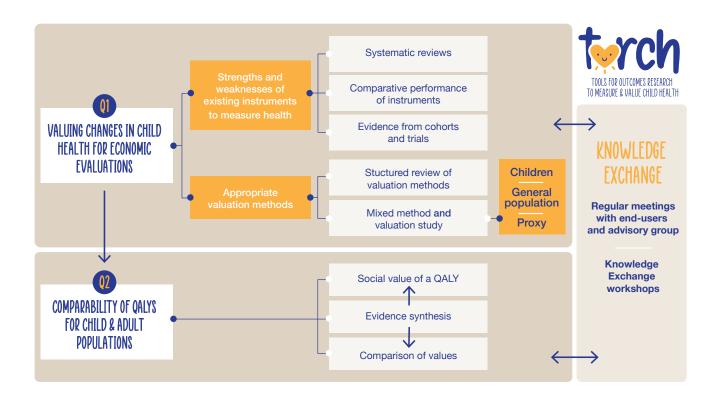
(ii) comparability of QALYs for child and adult populations.

The study will utilise 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 to address the research questions.

The study will involve meaningful collaborations between researchers, policymakers, clinicians, child health organisations, and importantly, young people, to co-design research. Collaboration will ensure that research outcomes are 'fit-for-purpose' and enable knowledge exchange between researchers and policymakers.

Click here to hear more from the team.

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



## Meet the team

We are an international team of researchers and clinicians, from seven universities across Australia and the United Kingdom. As a team, we bring together cross-cutting research methodologies to develop innovative solutions to measure and value child health.



Prof Emily Lancsar The Australian National University



Prof Kirsten Howard University of Sydney



Prof Stavros Petrou University of Oxford



Dr Elisabeth Huynh The Australian National University



Dr Martin Howell University of Sydney



Prof Joanna Coast University of Bristol



A/Prof Alison Hayes University of Sydney



Prof Jonathan Craig Flinders University



Prof Germaine Wong University of Sydney



Prof Cam Donaldson Glasgow Caledonian University



Prof Stacy Carter University of Wollongong



Dr Marcus Sellars The Australian National University



Dr Rakhee Raghunandan University of Sydney



Mr Joseph Kwon University of Oxford



Ms Jolene Cox The Australian National University

### TORCH 'out-and-about'

#### New publications

Our first review 'Systematic Review of Conceptual, Age, Measurement and Valuation Considerations for Generic Multidimensional Childhood and Patient-Reported Outcome Measures' has been published at PharmacoEconomics. This review was a joint collaboration with QUOKKA Research Program. Click here to access the review!

#### **Recent presentations**

Australian Health Economics Society Conference (21 and 22 September 2021) Associate Professor Alison Hayes presented on the "Psychometric Properties of Paediatric Quality of Life Measures: A Protocol". The TORCH research team met with our End User Group, Advisory Board and Associate Investigators in November 2021.

## *Kids to Adults: Chronic Illness Alliance Meeting* (16 December 2021)

Professor Emily Lancsar and Associate Professor Alison Hayes presented at the Kids to Adults: Chronic Illness Alliance (K2A Alliance) meeting.

#### Upcoming presentations

Our first Knowledge Exchange Workshop will be held in early 2022.











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