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Welcome Message

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

In this issue, the Research Spotlight is on two of our Chief Investigators: Dr Elisabeth Huynh from The Australian National University and Professor Stavros Petrou at The University of Oxford.

We update you on our new publications and our activity at the ISPOR- Australia Chapter Workshop in Sydney.

TORCH is in its last six months of research. We will be conducting a dissemination workshop in Canberra at the end of August. For details please [contact us](#).

We hope you enjoy this issue of our TORCH newsletter.

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 two of our Chief Investigators, Dr Elisabeth Huynh from The Australian National University and Professor Stavros Petrou at the University of Oxford.



Dr Elisabeth Huynh
The Australian National University

Dr Elisabeth Huynh is a Chief Investigator on the TORCH project, and part of the TORCH leadership team of Professor Emily Lancsar (ANU), Professor Kirsten Howard (USyd), Professor Stavros Petrou (Oxford) and Dr Martin Howell (USyd). Within TORCH, Elisabeth co-leads three work packages and contributes to several other work packages.

Elisabeth is a Senior Research Fellow in the Department of Health Economics, Wellbeing and Society (DHEWS) at The Australian National University (ANU). Her broad research interests lie in understanding and modelling choice, preferences and behaviour of key decision-makers in the health sector, particularly, though not exclusively, through discrete choice experiments (DCEs), and the use of such outcomes in economic evaluation. From a health applied policy perspective, her research is strongly focused on health sector and public policy decision making by patients and decision makers.

Elisabeth completed her PhD in Econometrics at the University of Sydney. Before joining ANU, she held appointments at the Institute for Choice at the University of South Australia (UniSA) (Postdoctoral/Research Fellow), the Centre for Study of Choice at the University of Technology Sydney (UTS) (Postdoctoral Research Fellow/senior research assistant).

What led you to the TORCH project?

TORCH brings together a number of my research interests, especially the focus on valuing quality of life and wellbeing in vulnerable populations and using stated preference methods such as DCEs to do so. I have previously been involved in the development and valuation of health-related quality of life, including CHU-9D for adolescents in Australia, as well as quality of life measures based on the capability approach (ICECAP-A, ICECAP-O, and ICECAP-SCM). My work in these areas naturally led me into working on TORCH and the team I am working with.

How has TORCH helped you as a researcher?

As part of TORCH, I've been involved in qualitative interviews with young people and their caregivers, which has been incredibly insightful and fascinating. I've gained valuable insights into designing stated preference studies to better engage children ages 10 and above and navigating the nuanced perspectives of young people ages 15 years old and above. Their willingness to delve into ethically challenging topics, such as the allocation of health resources for child health, has helped me better understand and appreciate decision-making in young people. I have also learnt a lot about the decision dynamics between parents and children dyads and that has helped me think about the different decision and choice processes people have and the implications of my own research as well as their implications for both policy and broader research. I am excited to being more involved in this type of work in the future.

What's been the best thing about working on TORCH?

The most rewarding aspect of my involvement in TORCH has been the opportunity to collaborate with an incredibly diverse and talented team. We have a very large core team of Chief Investigators, Associate Investigators and End Users. Everyone is friendly, collegial and respectful. I feel like everyone on TORCH shares a genuine interest and drive 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.

Researcher Spotlight



Professor Stavros Petrou
The University of Oxford

Stavros Petrou is the Academic Lead in Health Economics and Professor of Health Economics at the Nuffield Department of Primary Care Health Sciences, University of Oxford. He was previously Professor of Health Economics at the University of Warwick, where he still holds an honorary appointment. His research portfolio draws from a diverse funding base and covers both policy-relevant economic evaluations of diverse interventions and methodological work. A core theme of his research over the past 20 years has been the study of economic aspects of perinatal and paediatric health and healthcare, encompassing trial-based economic evaluations, economic evaluations based on decision-analytic models, systematic reviews, preference elicitation studies, and analyses of both cross-sectional data and cohort study data using econometric techniques. He is one of only two health economists to have held a UK MRC Senior Non-Clinical Research Fellowship. He was elected a National Institute of Health and Care Research (NIHR) Senior Investigator in 2017 (term two commenced in 2021), joining a body of England's leading 200 applied health researchers, and one of only four health economists in England to currently hold this award. He has served as a core member of a number of research funding panels, and currently serves on a number of external committees and editorial boards. He serves as a mentor to early and mid-career academic researchers through the Academy of Medical Sciences, the NIHR, and the UK Health Economists' Study Group (HESG).

What led you to the TORCH project?

I was approached by Emily Lancsar in late 2019 to join a consortium of researchers working on a research proposal aimed at developing new tools to measure and value child health. It seemed a unique opportunity to focus on methodological developments in an area I had been working in for many years. I was acutely aware of the need for new preference-based measures that are validated for use in mid and late childhood. Coming from an environment where there's a paucity of targeted funding for methodological research, I jumped at the opportunity to collaborate on the proposal. The decision was made even easier when I realised that Emily was assembling such a strong team to work on the proposal. The experience of working on the TORCH project since 2020 has only confirmed that it was a very wise decision to join the TORCH team.

How has TORCH helped you as a researcher?

I previously had experience of conducting a number of different types of research studies, but working on TORCH has allowed me to learn about methods and approaches I was less familiar with. For example, one of the studies we've conducted assessed the psychometric performance (i.e. assessed different forms of practicality, reliability, validity and so on) of generic childhood multi-attribute utility instruments (measures that describe self- or proxy-reported health status across multiple dimensions and generate health utilities). This meant collaborating with psychometricians and learning about how to interpret psychometric evidence. I'll hopefully build on this learning in my future research.

What's been the best thing about working on TORCH?

I'll highlight two benefits of working on the TORCH project. First, working with such a talented multi-disciplinary team. I invariably come away from TORCH meetings feeling that I've learnt something new or with an embryo of an idea for a future research study. The stimulation from working with the research fellows has been tremendous. Second, there's a real sense that the work that we're doing is going to influence health care decision-making in Australia and beyond, and ultimately that's what we want – to do good quality research that will impact policy.

Workshops

ISPOR Australian Chapter

ISPOR embraces health care researchers from all disciplines conducting health care research in Australia. These disciplines include all those with a focus on health economics, epidemiology, decision analysis, modelling, risk assessment, patient-reported outcomes (quality of life), use of 'real world' data such as health care database analyses, observational studies, patient register.

Measuring and valuing paediatric health related quality of life for use in economic evaluation: Issues and solutions

There are a set of well established tools that are used to inform Government decision making about what interventions and treatments to fund. However, approaches to measuring and valuing health-related quality of life (HRQoL) that are widely used and accepted in adults are problematic when applied to paediatric populations. Therefore there has been low uptake of these tools in the evidence used to inform healthcare decisions which risks misallocation of funds, potentially denying access to effective and cost-effective paediatric interventions.

This one day workshop focused on cutting edge research being done by two MRFF funded projects (QUOKKA and TORCH) to resolve these issues, and develop and refine methods for the measurement and valuation of child health. This included presentations by the project teams, consumers, policy makers, and PhD students. There was also a panel discussion focused on policy issues relating to the allocation of health resources to paediatric populations.

TORCH Dissemination Workshop

The TORCH team are in their last six months of the MRFF funded grant. To that end we are looking to a dissemination workshop which will be held on Wednesday August 28, 2024 at the National Portrait Gallery here in Canberra. Further details to come but feel free to contact us if you have any queries. And please, save the date!

Publications

All TORCH publications to date are available on our website as a [downloadable PDF](#).

New publications

Marcus Sellars, Stacy M. Carter, Emily Lancsar, Kirsten Howard, Joanna Coast. Making recommendations to subsidize new health technologies in Australia: A qualitative study of decision-makers' perspectives on committee processes. *Health Policy*, Volume 139, 2024.

<https://doi.org/10.1016/j.healthpol.2023.104963>

Bailey, C., Howell, M., Raghunandan, R. et al. The RETRIEVE Checklist for Studies Reporting the Elicitation of Stated Preferences for Child Health-Related Quality of Life. *Pharmacoeconomics* 42, 435–446 (2024).

<https://doi.org/10.1007/s40273-023-01333-z>

The RETRIEVE Checklist was also accepted into the [EQUATOR Network Library](#).



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