

January 2025 TASK Newsletter

Double down on science!

Dear friends and colleagues,

As I write this, many of us are experiencing profound challenges and uncertainty, either directly, or indirectly through loved ones, colleagues or friends. Whether the effects are from war, famine, wildfire, racism or political ill winds – whether they are occurring on distant continents or more locally -- no one is immune. In 2024, we witnessed a full eclipse. It seemed not only was the sun in eclipse, but also truth and unity. So how do we respond? What can we as pediatric researchers do? We can do what we do best: science. Let us re-commit ourselves to the highest standards of rigorous research to deliver evidence to help children and families get access to and receive the care they need and deserve around the world. May our research produce not only knowledge, but also wisdom, hope and light to brighten the path ahead for all.



Full solar eclipse, Adirondack Mountains, April 2024.

Wishing all of you a safe, secure and peace-filled 2025!

Wendy



News

TASK is proud to announce that two University of Toronto TASK students completed their MSc degrees in 2024. Aranie Vijayaratnam successfully defended her MSc thesis, [Cost-Effectiveness Analysis of a Parent-Training Program for Children with Neurodevelopmental Disabilities](#) on August 28. Roaa Shoukry successfully defended her MSc thesis, *Cost-Effectiveness Analysis of Mega Team for Cognitive Rehabilitation in Children with Attention-Deficit/Hyperactivity Disorder* on December 11. These dissertations represent highly original research expected to make important contributions to informing funding of treatment options for children with neurodevelopmental disabilities.

In 2024, Wendy J. Ungar was invited by the UK Academy of Medical Sciences to join an expert roundtable to advise on [Prioritizing early childhood to promote the nation's health, wellbeing and prosperity](#).

Awards

Again in 2024, Wendy Ungar ranked in the top 0.05% of all scientists worldwide by [Scholar GPS](#) for outstanding performance in the field of economic evaluation based on publication record, impact of work, and the quality of scholarly contributions.

Study Updates

Cost-effectiveness of genome sequencing in pediatric populations

With extended funding from Genome Canada, TASK continues to investigate the value of genome-wide sequencing (GWS) and genetic services in diverse pediatric patient populations. A cost-effectiveness analysis of genome vs. exome sequencing in pediatric rare diseases was completed in 2024. Watch out for our technical report and manuscript coming in 2025!

With funding from the Canadian Institutes of Health Research, TASK continues its collaborative research to examine the cost-effectiveness of returning secondary findings in pediatric populations with rare diseases.

TASK was awarded funding as part of two Canadian Institutes of Health Research team grants. The TRIAGE-GS study (G. Costain, PI) is a randomized comparison of obtaining sequencing results prior to the first medical geneticist visit versus usual care to understand the impact of a genome-first approach on incremental costs, diagnostic yield and time to diagnosis. In the K2A-RD study (K. Boycott, PI), using data from Genome Sequencing Ontario, TASK will develop a health state transition model to compare the costs and consequences of alternative positioning of genome and exome sequencing in the diagnostic pathway for rare pediatric diseases.

TASK continues in actively collaborating with Hayeems et al. on the development of psychometric tools to quantify clinical utility (C-GUIDE) and personal utility (P-GUIDE) of emerging genetic testing technologies in diverse populations and settings.

Measurement of preferences for health states in children and families

A significant gap in pediatric HTA is the lack of tools for measuring preference-based health-related quality of life (utilities) for calculating quality-adjusted life years (QALYs). In 2023-2024, Wendy Ungar guest edited a [special issue of Pharmacoeconomics](#) focusing on this subject.

Ungar WJ, Herdman M. [Meeting the challenges of preference-weighted health-related quality of life measurement in children](#). *PharmacoEconomics* 2024, 42(Suppl 1):3-8,

A central focus of TASK methods research is re-defining quality of life to consider the dynamic impacts among family members. A highlight was the work of former PhD student R. Lamsal published in 2024 to examine how spillover effects of pediatric illness on family members are incorporated into economic evaluations:

Lamsal R, Yeh A, Pullenayegum E, Ungar WJ. [A systematic review of methods and practice for integrating maternal, fetal, and child health outcomes, and family spillover effects into cost-utility analyses](#). *Pharmacoeconomics* 2024, 42:843-863.

Lamsal R, Yeh A, Pullenayegum E, Ungar WJ. [A systematic review of methods used by pediatric cost-utility analyses to include family health spillover effects](#). *Pharmacoeconomics*, 2024; 42(12):199-217.

Neurodevelopmental disorders: Services, costs, and cost-effectiveness:

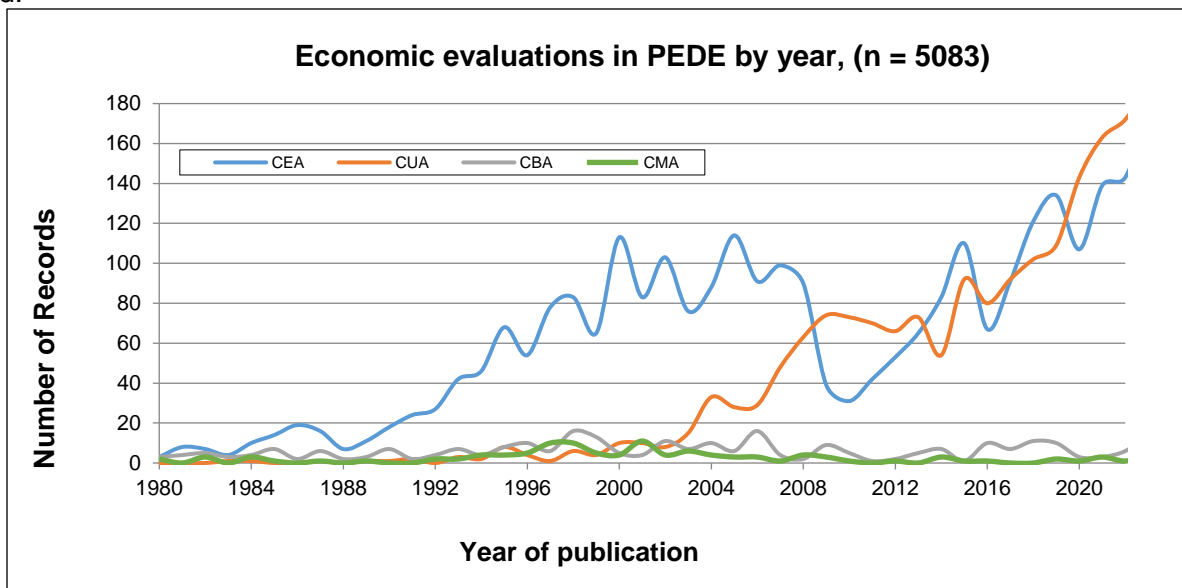
[The CHILD-BRIGHT Network](#) is a pan-Canadian collaboration between children's hospitals across Canada to study novel interventions in children with lifelong brain-based developmental disabilities. TASK, in collaboration with Dr. Jennifer Zwicker at University of Calgary and Dr. Myla Moretti at the SickKids-based Ontario Child Health Support Unit, are conducting cost-effectiveness analyses using patient-level data from multiple randomized controlled trials.

Vercancy Wu is currently estimating the cost-effectiveness of the [CCENT program \(Coached, Coordinated, Enhanced Neonatal Transition\)](#), which was designed to provide crucial support to high-risk infants during transition after discharge. This study is comparing resource use, costs, parental stress and quality of life of parents receiving access to a nurse navigator program after NICU discharge compared to usual care. Results are coming in 2025!

Dr. Zwicker's team is conducting economic evaluations for two CHILD-BRIGHT projects: the [SPORT \(Stimulation for Perinatal Stroke Optimizing Recovery Trajectory\) trial](#) focusing on children with perinatal stroke to assess the cost-effectiveness of non-invasive brain stimulation in improving motor skills. The [BRIGHT Coaching trial](#) examines a developmental coach system to empower families of preschoolers with developmental delays. The goal is to evaluate the cost-effectiveness of a standardized online education tool and coaching resource for parents during the transition from preschool to school entry. Two publications are planned for 2025.

Pediatric Economic Database Evaluation (PEDE) Update

The [PEDE Project](#) includes a database regularly maintained by TASK. The database consists of all pediatric economic evaluations published since 1980. The database has been updated with all publications from 1980 to 2023, with a total of 5083 studies and 5192 health utility weights. This freely accessible user friendly tool is used by researchers and HTA agencies around the world.



In 2024 for the first time, machine learning methods will be applied to simplify and streamline the review process. Feel free to contact us if you are interested in collaborating on studies using the PEDE database.

Scan the QR code below and explore the database:



Invited and Conference Presentations

In January 2024, Dr. Wendy Ungar was invited to address the Women in Science and Engineering National Conference as part of the Health Policy Panel and in March 2024 delivered a top-ranked platform presentation at the American College of Medical Genomics (ACMG) Annual Meeting on *A micro-costing and cost-effectiveness analysis of genome sequencing versus exome sequencing in pediatric rare diseases*.



Wendy Ungar delivers platform presentation at ACMG March 2024.

Dr. Ungar organized and delivered two oral presentations at the May 2024 International Society of Pharmacoeconomics and Outcomes Research (ISPOR) Annual Meeting. She participated in a panel on *Capturing family member spillover health effects in economic evaluation of pediatric interventions: Avoiding the landmines* with M. Tilford and R. Lamsal and *Developing preference-based health-related quality-of-life instruments for young children and infants: What's the best way to proceed?* with S. Grosse, T. Lavelle and K. Dalziel.

At the June 2024 ELSIcon meeting, Dr. Ungar spoke on *Incorporating equity considerations in health technology assessment and funding of genome medicine technologies in Ontario, Canada* and participated on a panel addressing *Global perspectives on implementing clinical genomic sequencing equitably, effectively and efficiently*. In September 2024 at the Canada Drug Agency (CDA) Annual Symposium, Dr. Ungar gave a talk on *23 and (not just) me: Incorporating family members in economic evaluation of genetic testing technologies* and participated on two panels: *Incorporating the child's perspective in health technology*

assessment in Canada, and the 'standing room only' *From disruption to opportunity: What can HTA learn from Taylor Swift?* Dr. Ungar was also an invited speaker at the November 2024 ISPOR EuroQoL Symposium, "Using HRQoL data from children and youth to strengthen HTA. What are the barriers? How can we improve current practice?" in Barcelona, Spain, where she spoke about *Novel strategies for assessing preferences for pediatric health states*.

In 2024, TASK staff, trainees and collaborators presented a total of 46 oral and posters presentations at international, national and local meetings.

For more information about TASK research activities, HTA reports and publications, please visit us at: <https://lab.research.sickkids.ca/task/> or scan the QR code below.



Grand Prismatic Springs, Yellowstone National Park, Wyoming, USA, August 2024.

A short poem by Dhayo Khangsar

I look at myself
and cry with courage on how far I have come.
I look at myself
and smile with determination on how much I can go further.

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