2026 TASK Newsletter

Dear friends and colleagues,

As I write this, our world continues to be one filled with profound global and domestic challenges and uncertainty. Truth seems harder and harder to find. But as scientists, we are skilled in truth-finding. Not only how to find it, but also how to test it, and how to communicate it – free from error, free from bias, and free from agendas. Let's use those skills: doubt what you hear, test what you're told, examine your sources!

Spring is budding in Toronto. May it bring renewal, hope and unity.

Peace,

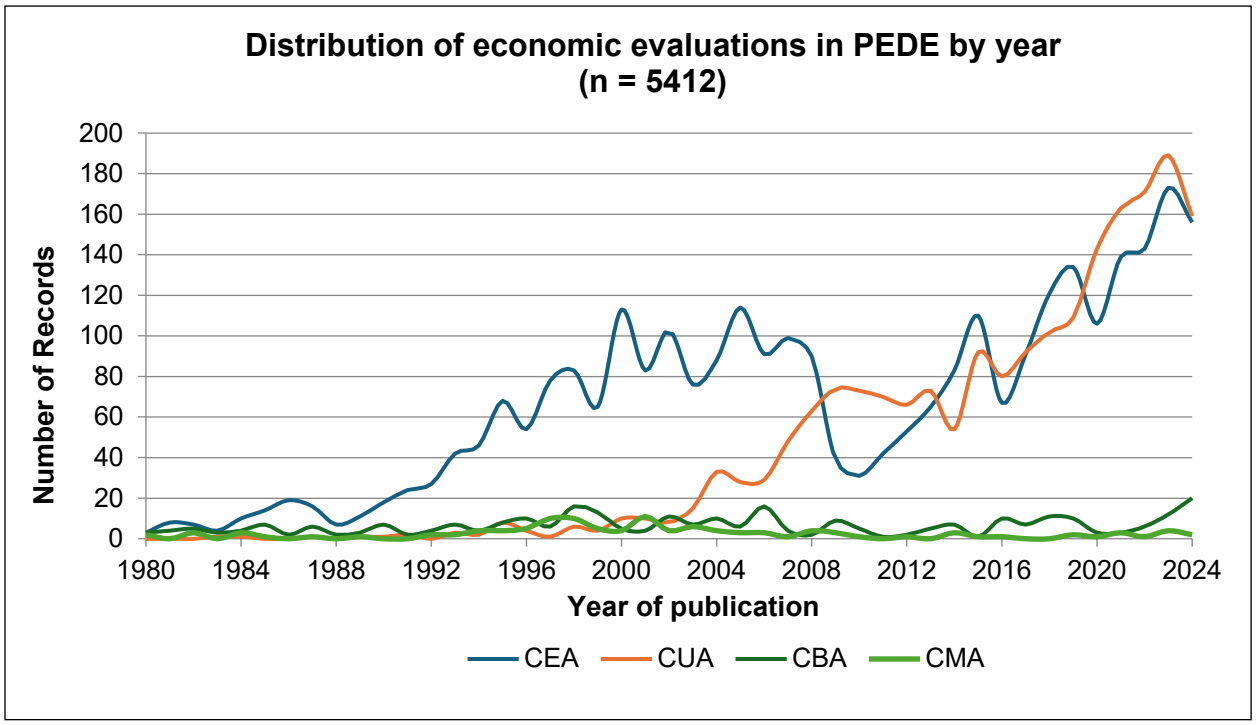
Wendy

News

The PEDE Project launches New Website!

Our PEDE Project website has a new look! The internationally acclaimed PEDE Project includes an online database consisting of all pediatric economic evaluations published since 1980. The database is updated annually, with a total of 5412 studies and 5775 health utility weights. This freely accessible user-friendly digital tool is used by researchers and HTA agencies around the world. With a more friendly user interface, the search page is now easy to use across all devices, with updated security features and the ability to download search output into .csv format. Please try out the new site by scanning the QR code below and be sure to update your links: https://lab.research.sickkids.ca/task/pede/

Feel free to contact us if you are interested in collaborating on studies using the PEDE database.



Study Updates

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. In collaboration with Dr. Jennifer Zwicker at University of Calgary and Dr. Myla Moretti at the SickKids-based Ontario Child Health Support Unit, The TASK Force is conducting cost-effectiveness analyses using patient-level data from multiple randomized controlled trials.

As part of her MSc thesis, Aranie Vijayaratnam examined the cost-effectiveness of a parent-training program for parents of children with neurodevelopmental disabilities such as autism. Manuscripts are in progress for: 1) an incremental cost-utility analysis of parent-training compared to usual care from the perspectives of the public sector and family payers and 2) an analysis comparing resource use, costs and productivity impacts between groups from the family perspective. Roaa Shoukry is in the process of preparing two manuscript from her MSc thesis on the cost effectiveness analysis of a video game for cognitive rehabilitation in children with attention deficit/hyperactivity disorder: 1)) an

incremental cost-utility analysis of the video game compared to usual care from the perspectives of the public sector and family payers and 2) an analysis comparing resource use, costs and productivity impacts between groups from the family perspective.

Vercancy Wu has completed a cost analysis of the CCENT program (Coached, Coordinated, Enhanced Neonatal Transition), which provides support to families of infants with medical complexity during transition to home after discharge from the neonatal intensive care unit. This study compared resource use and costs from a healthcare system and family perspectives. A paper is currently under review in the journal, *Children*.

Laura Diamond published a commentary on mental health supports for parents of newborns with medical complexity.

> Diamond L, et al. Mental disorders among postpartum individuals with medically high-risk infants or obstetrical complications: A population requiring further attention. *Paediatrics & Child Health.* 2025;30(7):535-539.

Dr. Zwicker is supervising economic evaluations for two CHILD-BRIGHT projects. The SPORT (Stimulation for Perinatal Stroke Optimizing Recovery Trajectory) trial assessed the cost-effectiveness of non-invasive brain stimulation in improving motor skills in children with perinatal stroke. A manuscript is in progress. The BRIGHT Coaching trial examined a developmental coach system to empower families of preschoolers with developmental delays. A cost analysis from a family payer perspective is now published:

> Xiao Yang J, et al. Parent coaching program for children with emerging developmental disabilities while on a waitlist for services: Cost analysis from a family payer perspective. *BMC Pediatrics*. 2026;26(1):319.

Measurement of preferences for health states in children and families

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 Ramesh Lamsal, to examine how spillover effects of pediatric illness on family members are incorporated into economic evaluations. Two recent papers include:

> Lamsal R et al. Impacts beyond the child: A theoretical framework of pediatric economic evaluation from a family perspective. *Social Science & Medicine.* 2026;397:119096.
>
> Lamsal R, et al. Quality of life, productivity loss, and mental health service utilization among parents of children with neuroinflammatory disorders: A cross-sectional study. *Multiple Sclerosis and Related Disorders*. 2026;107:107032.

Cost-effectiveness of genome sequencing in pediatric populations

With extended funding from Genome Canada, TASK continues to investigate the value of genome-wide sequencing and genetic services in pediatric patient populations. A cost-effectiveness analysis of genome vs. exome sequencing in pediatric rare diseases was completed and a detailed technical report and publications are now available:

> Wu V e al. A micro-costing and cost consequence analysis from a randomized controlled trial comparing genome sequencing to exome sequencing for genetic diagnosis. TASK Report No. 2025-01. Available at: http://lab.research.sickkids.ca/task/reports-theses/
>
> Ungar WJ, et al. A microcosting and cost consequence analysis from a randomized controlled trial comparing genome sequencing to exome sequencing for genetic diagnosis. *Genetics in Medicine*. 2026;28(2):101561.
>
> Hayeems RZ, et al. Comparing the performance of exome and genome sequencing for rare disease diagnostics: A randomized implementation effectiveness trial. *Genetics in Medicine.* 2026;28(1):101605.

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. The clinical protocol has now been published:

> Assamad D, et al. Understanding the impact of secondary findings on clinical care and patient experience: The secondary findings impact study protocol. *BMJ Open.* 2026;16(3):e115821.

TASK is collaborating on 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. The protocol has been published:

> Stanley KJ, et al. TRIAGE-GS: Protocol for a randomized controlled trial of a genomics-first approach to rare disease diagnosis for patients awaiting assessment by a clinical geneticist. *BMJ Open.* 2025;15(8):e107603.

In the K2A-RD study (K. Boycott, PI) using data from Genome Sequencing Ontario, TASK is developing a decision 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 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.

Invited and Conference Presentations

In July 2025, members of TASK attended the International Health Economics Association (iHEA) Congress held in Bali, Indonesia. Dr. Ungar presented, “23 and (not just) me: Incorporating family members in economic evaluation of genetic and genomic testing technologies” and “Assessing preferences for pediatric health states from a family perspective.” Dr. Myla Moretti presented, “Navigating transition to home: Resource use and cost comparison of nurse navigator support for caregivers of high-risk infants post-NICU.”

Dr. Myla Moretti, IHEA Congress, Bali, Indonesia, July 2025

In October 2025, talks were also delivered by Dr. Ungar on HTA of genetic/genomic tests in Ontario as part of a standing-room-only panel organized by Dr. Robin Hayeems on “Bridging the Evidence Gap” at the Canadian College of Medical Geneticists and Canadian Association of Genetic Counselors Joint Annual Meeting in Banff, Alberta.

From January 2025-present, TASK staff, trainees and collaborators presented a total of 34 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.

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