

## February 2024 TASK Newsletter

Dear friends and colleagues,

In the past year, we have witnessed AI and machine-learning algorithms gain traction in the delivery of health services for children. These tools are making significant contributions to data-rich specialties such as imaging and diagnostics and are increasingly being combined with dynamic clinical and administrative data to improve prediction of health outcomes. The black box is getting bigger. As researchers we must advocate for the fair and full evaluation of these technologies to ensure that only value-added tools are paid for. The opportunity costs include wasting scarce health care dollars and resources, and exacerbating inequities between institutions, and consequently patients. And another ever growing opportunity cost is the increase in complexity in patient management among practices and institutions that rely so heavily on technology. While some AI and ML technologies are no doubt welcomed and needed, let's devote at least as much attention to using them to streamline care, reduce waste and improve communication and data-sharing between practices, institutions, and patients.



Night View in Lanzhou, Gansu, China. Photo by V. Wu, 09/27/2023

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Wishing all of you a safe and peace-filled 2024!

*Wendy*



### News

In 2023, Wendy J. Ungar was re-appointed for another three-year term as Chair of the Ontario Genetics Advisory Committee, the HTA decision-making committee that reviews evidence to inform funding recommendations for genetic and genomic technologies for Ontario, Canada's publicly-funded healthcare system. This HTA committee uses a bespoke value framework for prioritizing and for assessing the value of genetic/genomic technologies. To learn more about the committee, please click [here](#).

Wendy Ungar served on an international working group led by Ed Henry, University of Galway, to provide guidance for inclusion of spillover effect in economic evaluation to generate more robust evidence for decision-making: [Spillovers in Health Economic Evaluation and Research \(SHEER\) Task Force: Emerging good practice and recommendations for a future research agenda](#).

Wendy Ungar and Mike Herdman are Guest Editors for a Special issue of *PharmacoEconomics: Advancing measurement of children's health-related quality of life- evidence from the QUOKKA (Quality OF Life in Kids: Key evidence to strengthen decisions in Australia) research program*. This growing collection will make a substantial contribution to the evidence base regarding the measurement and valuation of pediatric health states.

## Awards

In 2023, Aranie Vijayaratnam was awarded the People's Choice Award at the Geospatial Data Visualization Challenge event held by the University of Toronto Dalla Lana School of Public Health (DLSPH) and was also awarded the Implementation Science Trainee Presentation Award by the DLSPH in 2023.

Roaa Shoukry and Aranie Vijayaratnam received Travel Grants from the University of Toronto School of Graduate Studies, from the CHILD BRIGHT Network and from the Kids Brain Health Network to present their research at the 2023 CHILBRIGHT and Kids' Brain Health Annual Meetings.



Ottawa, Ontario, Canada, Photo by A. Vijayaratnam,

## Study Updates

### ***Cost-effectiveness of genome sequencing in pediatric populations***

With funding from Genome Canada and the Ontario Ministry of Health, TASK continues to investigate the value of genome-wide sequencing (GWS) and genetic services in diverse pediatric patient populations. Ongoing studies are examining the incremental cost-effectiveness of genome vs. exome sequencing as well as the cost-effectiveness of returning secondary findings in pediatric populations with rare diseases.

Ungar WJ, Hayeems RZ, Marshall CR, Gillespie MK, Szuto A, Chisholm C, Stavropoulos DJ, Huang L, Jarinova O, Wu V, Tsiplova K, Lau L, Lee W, Venkataramanan V, Sawyer S, Mendoza-Londono R, Somerville MJ, Boycott KM and the Genome Sequencing Ontario Secondary Findings Study Team. [Protocol for a prospective observational cost-effectiveness analysis of returning secondary findings of genome sequencing for unexplained suspected genetic conditions](#). *Clinical Therapeutics* 2023; 45(8):702-709.

TASK is 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.

### ***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). Work led by

former post-doctoral fellow Naaz Bashir examined the validity and reliability of the CHU-9D, a pediatric centred instrument.

Bashir NS, Walters TD, Griffiths AM, Otley A, Critch J, Ungar WJ. [A comparison of the Child Health Utility 9D and the Health Utilities Index for estimating health utilities in pediatric inflammatory bowel disease](#). *Quality of Life Research*, 2023; 32(9):2527-2539.

Bashir NS, Walters TD, Griffiths AM, Otley A, Critch J, Ungar WJ. [A comparison of preference-based, generic and disease-specific health-related quality of life in pediatric inflammatory bowel disease](#). *Journal of the Canadian Association of Gastroenterology*, 2023; 6(2):73-79.

A central focus of TASK methods research is re-defining quality of life to consider the dynamic impacts among family members. Specifically, caregiver health outcomes were studied by PhD student Christine Belza.

Belza C, Avitzur Y, Ungar WJ, Stremler R, Fehlings D, Wales PW. [Stress, anxiety and health-related quality of life in caregivers of children with intestinal failure on parenteral nutrition: A cross-sectional survey study](#). *Journal of Parenteral and Enteral Nutrition*, 2023; 47(3):342-353.

Related to this was research to examine how spillover effects of pediatric illness on family members is incorporated in economic evaluation of pediatric interventions performed by former PhD student R. Lamsal:

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.

And the work by the SHEER Task Force:

Henry E, Al-Janabi H, Brouwer W, Cullinan J, Engel L, Griffin S, Hulme C, Kingkaew P, Lloyd A, Payakachat N, Pennington B, Peña-Longobardo LM, Prosser LA, Shah K, Ungar WJ, Wilkinson T, Wittenberg E. Spillovers in Health Economic Evaluation and Research (SHEER) Task Force: Emerging good practice and recommendations for a future research agenda. In press, *PharmacoEconomics* 2023.

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

Understanding the unique challenges of conducting economic evaluations of interventions for autism was described in our commentary and invited book chapter:

Tsiplova K, Ungar WJ. [Why it is so challenging to perform economic evaluations of interventions in autism and what to do about it](#). Tsiplova K, Ungar WJ. Why it is so challenging to perform economic evaluations of interventions in autism and what to do about it. *Autism Res*, 2023; 16(11):2061-2070.

Ungar WJ, Tsiplova K. [Economic evaluations of early intensive behavioral interventions for autism](#). Chapter 36, pp. 679-699 in Matson JL, Sturmey P (Eds), *Handbook of Autism and Pervasive Developmental Disorders*. Autism and Child Psychopathology Series. Springer Nature Switzerland AG: Basel, 2022.

[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 supporting Dr. Moretti on 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. The purpose of this study is to compare the 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.

Result of this study will provide evidence whether crucial support for families with high-risk newborns and, Dr. Zwicker's team is conducting economic evaluations for two CHILD-BRIGHT projects: this study [SPORT \(Stimulation for Perinatal Stroke Optimizing Recovery Trajectory\) trial](#) focuses on children with perinatal stroke and aims to assess the effectiveness of non-invasive brain stimulation in improving motor skills. The object is to evaluate whether this intervention can offer support to children's mobility in a cost-effective way. The [BRIGHT Coaching trial examines a developmental coach system to empower families of preschoolers with developmental delays](#).

The goal of the study is to evaluate the feasibility and effectiveness of a standardized and nationally available online education tool and coaching resource for parents during the transition from preschool to school entry, with a specific focus on its economic aspects nationally.

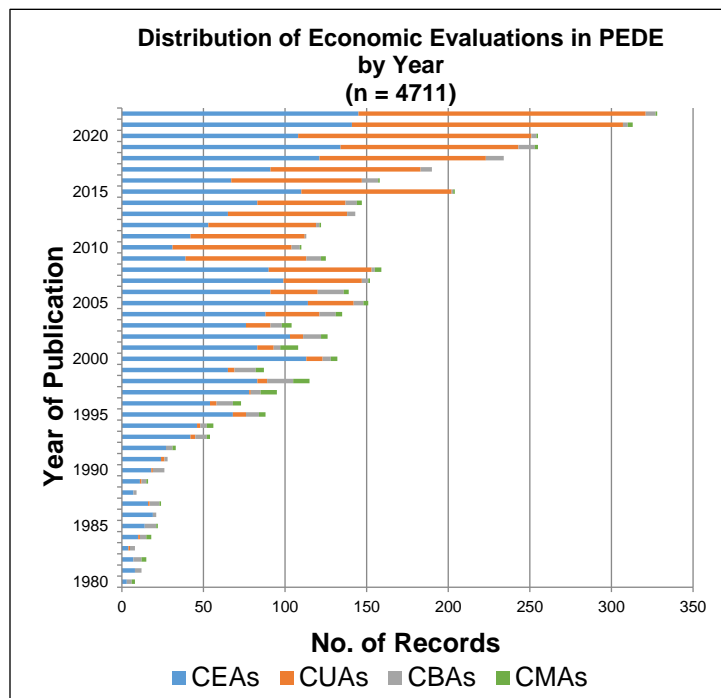


Toronto Reflected, Photo by W. Ungar

## Pediatric Economic Database Evaluation (PEDE) Update

The [PEDE Project](#) is a database regularly maintained by the team of [TASK \(Technology Assessment at SickKids\)](#). The database consists of all pediatric economic evaluations published since the year of 1980. The database has recently been updated with all publications from 1980 to 2022, with a total 4711 studies and 4540 health utility weights. Our [database](#) is user friendly with free of access, and easily searchable for all users around the world. 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

Wendy Ungar was invited to speak on “Health Technology Assessment and Funding of Genetic Prenatal Screening Technologies in Ontario” at the Canadian Fertility and Andrology Society Annual Meeting in September 2023 and “Economic evaluation in Child Health: Playing Outside of the Sandbox” for the Canadian Centre for Health Economics in March 2023.

TASK had the privilege of showcasing the remarkable work of its talented MSc students at both the Child-Bright Annual Meeting in Toronto on June 2023, and the Kids Brain Health Network (KBHN) annual conference held in Ottawa on October 2023.

Aranie Vijayaratnam presented her thesis research, “The Cost-Effectiveness of the Strongest Families Neurodevelopmental Program.” Her insightful exploration delved into the economic dimensions of the program, contributing valuable insights to the discourse on pediatric neurodevelopmental interventions.



Roaa Shoukry presented her thesis research, “A Cost-Effectiveness Analysis of the "Mega Team" for Cognitive Rehabilitation in ADHD.” Roaa's presentation shed light on the economic implications of the innovative 'Mega Team', providing a nuanced perspective on the cost-effectiveness of cognitive rehabilitation strategies.

In 2023, TASK staff, trainees and collaborators presented 44 oral and posters presentations at international and national 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.



### Lost childhood: A haiku poem by Dhayo Khangsar

A childhood unlived  
Should not be tolerated  
It must be condemned