Working Together: Terms of Reference for Patient Engagement

Co-creating guidance for patient engagement in economic evaluations

The Ottawa Hospital Research Institute | L'Hôpital d'Ottawa Institut de recherche

HERO Health Economics and healthcare Resource Optimization

These terms of reference are co-developed with patient partners to guide how we will work together throughout the DEEP-ENGAGE project.

This is a "living document", meaning it can be updated as the project evolves to reflect the team's needs and ensure it remains current and relevant.

- DEEP-ENGAGE Team

Impact and Significance

Our project aims to identify processes and develop guidance on integrating patient perspectives throughout the economic evaluation process, from start to finish. This approach addresses a key gap by ensuring evaluations reflect real-world patient experiences and priorities. By embedding patient input at every stage, we will promote transparency, inclusivity, and patient-centred decision-making in healthcare. Importantly, patient partners will contribute to current project activities and may also play a role in shaping the design and priorities of future health economic evaluations.

The resulting guidance will set new standards for economic evaluations, emphasizing patient-centred outcomes and societal benefits. In turn, this will inform healthcare policy and resource allocation in ways that better align with patients' needs and values. Ultimately, this work will advance the field of health economics and strengthen healthcare systems' commitment to patient well-being and equity.

Background and Rationale

Canada's healthcare spending reached 12% of its gross domestic product in 2023 (1), driven largely by an aging population and the growing prevalence of chronic diseases. Both of which require costly, ongoing medical care (2, 3). In response to these escalating costs, Health Technology Assessments (HTAs), particularly economic evaluations, are increasingly important in informing policy decisions to maximize health outcomes with limited resources (4). These evaluations help decision-makers allocate limited healthcare resources to maximize health outcomes, especially as demand continues to outpace funding.

Over the past two decades, there has been a growing emphasis on involving patients and the public in HTA processes. This shift aims to promote transparency, foster greater acceptance of HTA decisions and bring invaluable firsthand insights from patients living with specific health conditions and their caregivers (5). Patient engagement (PE) can occur throughout the entire HTA life cycle, from topic selection to dissemination and evaluation. However, the role of patients in specific components, such as economic evaluations, remains underdeveloped. Most economic evaluations still position patients as data sources rather than active collaborators. While recent efforts have engaged patients in the economic modelling process (6), this involvement has highlighted both the potential benefits, such as enhanced validity and alignment with patient priorities, and the challenges, including increased model complexity and communication difficulties.

Many health economists remain uncertain about how to engage patients effectively, and patients may feel tokenized or excluded from meaningful participation (7). These challenges underscore the need for clear, practical guidance on when, where, and how to involve patients meaningfully in economic evaluations. Balancing inclusive engagement with methodological rigour is essential to ensure that economic evaluations reflect what matters most to those directly affected by healthcare decisions.

Goals and Objectives

This project aims to co-create guidance on when and how to engage patients in economic evaluations, and on how to report and assess the impact of their engagement. Our specific objectives are to:

Summarize existing patient engagement guidelines and best practices and evaluate their relevance to economic evaluations.

Identify the researcher and patient partner barriers and supporting factors to patient engagement in economic evaluations.

Develop guidance on how to engage patients in economic evaluations, and on how to report and assess the impact of their engagement.

Timeline

Scoping Review

A review to explore existing reviews or guidance on patient engagement in health research. Findings will be summarized and used to identify key themes for consideration in the eDelphi survey.

Researcher Survey

An international survey of health services researchers who have conducted or reviewed economic evaluations, aimed at characterizing the current landscape of patient engagement in economic evaluation practice.

Qualitative Interviews

Semi-structured interviews with key interest groups – health economists, patient partners, and knowledge users (e.g. health technology assessment agencies and health care providers) on the value of patient engagement to gain insights into experiences engaging patients or being engaged as a patient partner and barriers to patient engagement in economic evaluations.

eDelphi Survey

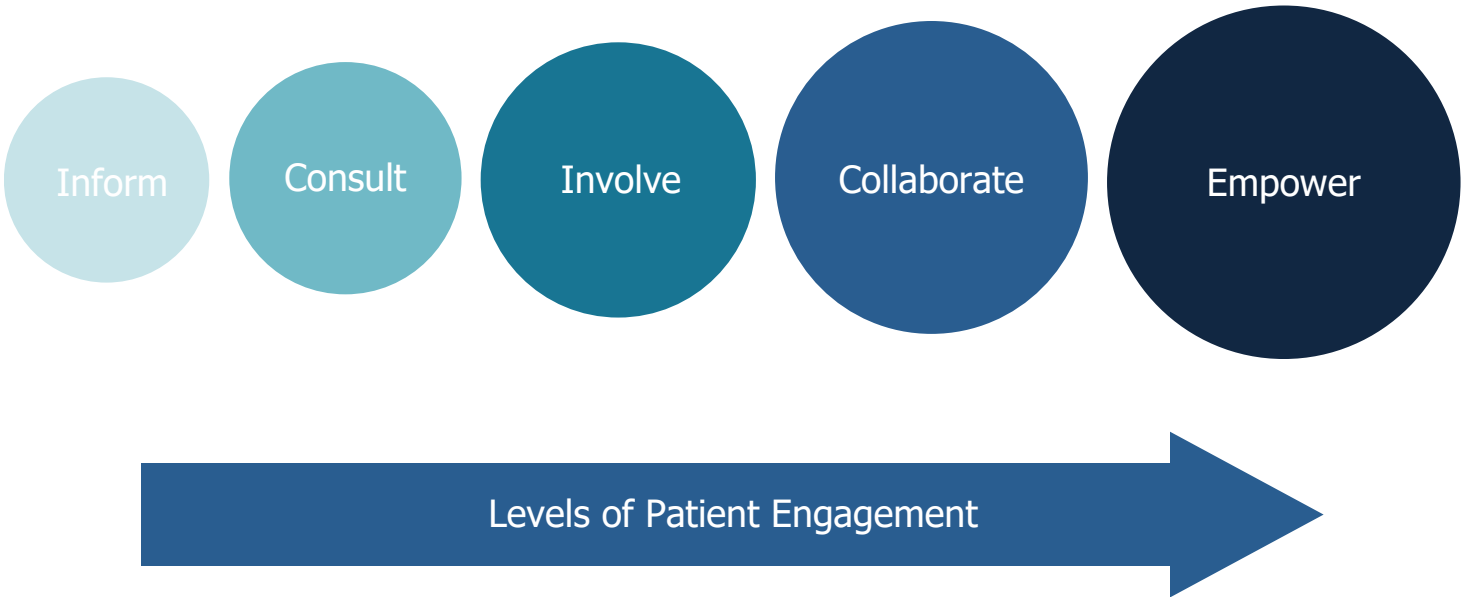
A three-round modified eDelphi survey to reach consensus on the key items for patient engagement in economic evaluations.

Consensus Meeting

A hybrid meeting to finalize the key items for guidance in patient engagement in economic evaluations.

Patient Engagement

In this project, we value the diverse ways that patients and caregivers can contribute to research. Throughout this document, we use the term "patient partners" to refer to individuals with lived or living experience of illness and their caregivers who contribute their expertise to the project. Guided by the Saskatchewan Centre for Patient-Oriented Research, Patient-Oriented Research Level of Engagement (SCPOR PORLET) (8), we aim to support a range of meaningful engagement opportunities across five levels: Inform, Consult, Involve, Collaborate, and Empower.



Patient partners may choose their level of involvement based on their interests, experience, and availability, and are welcome to adjust their participation as the project evolves. For some components of the project, patient partners may choose to participate at the Inform level, where they receive updates about project activities and findings. For other components, they may wish to participate more actively through consultation, collaboration, or partnership in research activities.

For each component of the project, patient partners may choose to:

- Be Informed: Patient partners may choose to stay updated on project progress and receive regular communications. They may not be actively involved in research design or decision-making but are considered valued members of the broader team.
- Be Consulted: In this role, patient partners are invited to provide feedback on project components—such as research questions, priorities, outcomes, or tools (e.g., surveys or interview guides)—which will be considered by the research team.
- Be Involved: Patient partners can contribute ideas that shape project decisions. For example, they may help prioritize outcomes, inform protocol design, or interpret findings. Their perspectives are consistently integrated into decision-making processes.
- Collaborate: Patient partners may take on equal roles with researchers in developing the project. This could include co-creating tools, co-designing the knowledge translation plan, or jointly interpreting results. Their contributions directly influence project direction, methods, and outputs.
- Be Empowered: Patient partners may take on leadership roles (e.g., co-investigator, co-principal investigator), where they share decision-making authority throughout the project. This includes co-identifying priorities, co-determining outcomes, and co-leading knowledge translation and policy discussions.

Patient Engagement

We are committed to supporting flexible and meaningful engagement across this continuum. Patient partners are encouraged to voice their interests in participating in any specific aspect of the project. Time will be set aside during team meetings to check in on patient partner satisfaction and explore opportunities for involvement that align with each person's interests, skills, and availability.

All patients, staff, and other members of the research team are invited to share ideas on how we can work together more effectively. Every suggestion is valued and helps us create a stronger, more inclusive research process.

To support these discussions, we have included the SCPOR PORLET Tool, which offers examples of how patients can be involved at different stages and levels of a research project (8). This framework can help patient partners to describe their preferred degree of involvement in various activities and guide research staff in reflecting on how well they facilitate meaningful engagement.

In this project, the "Inform" level is not considered patient engagement according to the Canadian Institutes of Health Research definition. While patient partners may choose the Inform level for certain components of the project, meaningful engagement requires participation at higher levels (e.g., Consult, Involve, Collaborate, or Empower) in at least some aspects of the work.

Confidentiality

During meetings and in email communications, you may learn about the personal experiences of others or wish to share your own during discussions to inform research activities. Creating a safe and respectful space for open dialogue is a shared responsibility. To support this, all team members, including patient partners, are asked to treat personal stories, experiences, and any sensitive information shared during meetings or email communications as confidential.

Please do not share private information outside of the project team or with individuals for whom it was not intended. Similarly, the research staff are committed to protecting your privacy. Any personal details, testimonials, or recordings will be stored securely and will not be shared with others without your explicit consent. For patient partners who wish to take on more active roles in specific components of the research, such as conducting or analyzing interviews, we encourage completing the TCPS 2: Core Tutorial (Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans) (9). This short, free online training introduces key ethical principles in Canadian research and helps ensure we all uphold high standards of privacy, respect, and integrity. The research staff are happy to assist with registration or provide support in completing the training, if needed.

If you have any questions about confidentiality or your role, please don't hesitate to contact the staff at any time.

Communications

Updates

The research staff will commit to providing regular updates to the team throughout the project, even during periods of low activity. Updates will be scheduled bi-monthly (every 2 months), although they may be delayed at times due to staffing levels and other responsibilities, or substituted with a team meeting.

Meetings

Depending on project stages and deadlines, the staff will aim to schedule patient partner meetings approximately every 4 months to discuss project progress and engagement methods. The meeting durations can vary but will likely take 60-90 minutes and will be scheduled on a date that works best for most members. Meetings will be held via MS Teams or Zoom, allowing users to join from a tablet, computer, or phone. We hope to organize an in-person meeting at some point in the project, provided adequate funding and interest.

In preparation for team meetings, the research staff will send the slides and/or agenda beforehand if possible. The team is encouraged to bring up items they wish to discuss at any time before, during, or after the meeting. The meetings will be video recorded, and the staff and/or transcription tools, including AI-enabled features available through Zoom or MS Teams, may be used to take minutes. If any member is unable to attend the meeting, they may review these materials to stay informed and send their opinions or responses via email afterward.

Communications

Methods

Communication among patient partners and the research staff will primarily occur via email, over the telephone as needed, and via video conferencing (i.e., Zoom or MS Teams) for meetings. The staff will be happy to explore other methods of communication if the standard methods are insufficient. The team now has a shared email (hero@ohri.ca) that is monitored daily by Cacy and Olivia to ensure a rapid response to any concerns. However, patient partners are also welcome to reach out to the Nominated Principal Investigator (NPI, Dr. Kednapa Thavorn at kthavorn@ohri.ca), particularly if you need to discuss any sensitive information. Partners will have access to a shared folder (e.g., OneDrive) containing important project documents (e.g., Terms of Reference, meeting materials, training materials, and references). This folder can be accessed from a computer or tablet.

Communications

Training

Patient partners will receive online training and resources to build a foundational understanding of health economic evaluations and other relevant aspects of the project. These materials are designed to support meaningful participation and ensure everyone feels informed and confident in their role.

If specific tools or platforms are needed for project activities, such as DistillerSR (for literature screening), hands-on training and support will be provided before use. Additionally, we are happy to provide guidance and technical assistance with common tools such as Zoom, OneDrive, and other Microsoft 365 applications, as needed.

We are committed to ensuring that all team members feel supported in participating fully. If you have questions or would like additional training or assistance at any point, please don't hesitate to let us know.

Contact

You are always welcome to reach out to the research staff at any point should you wish for further information or have concerns about the project and the status of our objectives. You can reach out to the research team's shared email at hero@ohri.ca, the NPI Kednapa Thavorn at kthavorn@ohri.ca, or the patient partner co-principal investigator (co-PI), Maureen Smith, at maureensmith137@icloud.com.

Accountability

Patient partners are valued contributors to this project, and we encourage their participation in reviewing, shaping, and implementing project activities. The level and type of engagement will vary based on each person's interests, availability, and comfort. Some roles may require more in-depth discussion or training, and we are committed to supporting you throughout.

Patient partners will never be expected to complete tasks alone or without adequate guidance, training, and collaboration. The research staff are responsible for ensuring you have the information, tools, and support needed to contribute meaningfully and confidently to any activity you choose to participate in.

If at any time you need clarification, additional discussion, or an accommodation to participate more fully, please reach out to the staff. We will do our best to address your needs in a timely and respectful way.

Accountability

During meetings or project updates, you may be asked to review documents or provide input on specific tasks. When feedback is time-sensitive, the research team will communicate reasonable deadlines and send reminders. If you are unable to contribute during a given period or have no additional comments, please let us know. There is no pressure to participate in every activity, and opportunities to engage will be available throughout the project.

The DEEP-ENGAGE team includes a patient partner co-principal investigator. This ensures that patient engagement updates and any issues that arise are part of the steering committee meetings and that there is always a patient perspective to inform decision-making.

Compensation and Reimbursement

We value the time, expertise, and lived experience that patient partners bring to this project. In recognition of their contributions, patient partners will be offered compensation in alignment with Canada's Strategy for Patient-Oriented Research (SPOR) Evidence Alliance (10).

This base compensation reflects ongoing contributions such as participation in team meetings, training sessions, and providing feedback on project components, including protocols, manuscripts, and presentations.

We also recognize that some partners may wish to take on additional roles or activities, such as co-developing tools or participating in data collection or analysis. These activities will be compensated an additional rate up to a maximum of 37.5 hours per year per partner (across all study activities combined), unless otherwise discussed with the NPI. To ensure timely and accurate processing, the research team will estimate and document additional activities and hours patient partners may have spent on this project. These records will be shared for validation with the patient partner co-PI and individual patient partners at the end of each project component or fiscal year.

Patient partner compensation and reimbursement will be provided in the format of your choice (e.g., electronic funds transfer or e-gift card). Compensation (base + any additional hours) is calculated at the end of each fiscal year (April 1 to March 31) of each year of the project. Any changes to additional hours in that year should be submitted to the research team by March 31st. Once payments have been submitted to our Finance department, it may take a few weeks to perhaps more than a month to be issued.

Tax Implications and Questions

Tax Implications

Any cash payment or gift cards totalling $500 or more in a calendar year is considered taxable income. The Ottawa Hospital Research Institute will issue a T4A for these payments. The T4A statements are sent by mail. Please ensure mailing address information is up to date with Jennifer, jebrownrigg@ohri.ca.

Tax-Related Questions

The HERO team is not able to answer tax-related questions. Compensation payments may alter the benefits status for individuals on disability, pension, or other forms of income.

To learn more about tax implications, please consider the following guidelines from the Canada Revenue Agency:

- Employment Income (includes honoraria)
- Receiving Gifts
- Gifts and Income Tax
- Expenses incurred by volunteers
- Community Volunteer Income Tax Program

If you have any questions about compensation or preferred payment, please don't hesitate to reach out. We are committed to ensuring transparency, fairness, and mutual respect in all aspects of our collaboration.

References

1. Information CIfH. National health expenditure trends: CIHI; 2023 [Available from: https://www.cihi.ca/en/national-health-expenditure-trends#:~:text=Total%20health%20spending%20in%20Canada,mere%201.5%25%20growth%20in%202022.

2. Nelson S, Whitsel L, Khavjou O, Phelps D, Leib A. Projections of Cardiovascular Disease Prevalence and Costs: 2015–2035. RTI International; 2016. Report No.: 0214680.003.001.001.

3. Sun H, Saeedi P, Karuranga S, Pinkepank M, Ogurtsova K, Duncan BB, et al. IDF Diabetes Atlas: Global, regional and country-level diabetes prevalence estimates for 2021 and projections for 2045. Diabetes Research and Clinical Practice. 2022;183:109119.

4. Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW. Methods for the Economic Evaluation of Health Care Programmes. 4th ed. Oxford: Oxford University Press; 2015. 445 p.

5. Wale JL, Thomas S, Hamerlijnck D, Hollander R. Patients and public are important stakeholders in health technology assessment but the level of involvement is low – a call to action. Research Involvement and Engagement. 2021;7(1).

6. Bunka M, Ghanbarian S, Riches L, Landry G, Edwards L, Hoens AM, Bryan S. Collaborating with Patient Partners to Model Clinical Care Pathways in Major Depressive Disorder: The Benefits of Mixing Evidence and Lived Experience. Pharmacoeconomics. 2022;40(10):971-7.

7. Harvard S, Werker GR. Health Economists on Involving Patients in Modeling: Potential Benefits, Harms, and Variables of Interest. PharmacoEconomics. 2021;39(7):823-33.

8. Research S-SCfP-O. PORLET & IRLET — Saskatchewan Centre for Patient-Oriented Research: SCPOR; 2025 [Available from: https://www.scpor.ca/porlet20.

9. Ethics PoR. TCPS 2: CORE-2022 (Course on Research Ethics). Panel on Research Ethics; 2022.

10. Alliance SE. Patient and Public Partner Financial Compensation Policy and Protocol. Toronto, ON; 2025.