

# Multi-Stakeholder Dialogue To Explore Uses Of Real-World Data For Decision-Making For Pediatric Low-Grade Glioma Care

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## Objective

With the support of Health Canada, CADTH has launched a learning period to explore the potential value of real-world data (RWD) to fill gaps in evidence and support decision-making about care for rare diseases. To learn by doing, CADTH coordinated a multi-stakeholder dialogue process to identify measurable indicators and outcomes that stakeholders consider relevant for decision-making about optimizing care for pediatric low-grade glioma (pLGG) in Canada.

## Methods

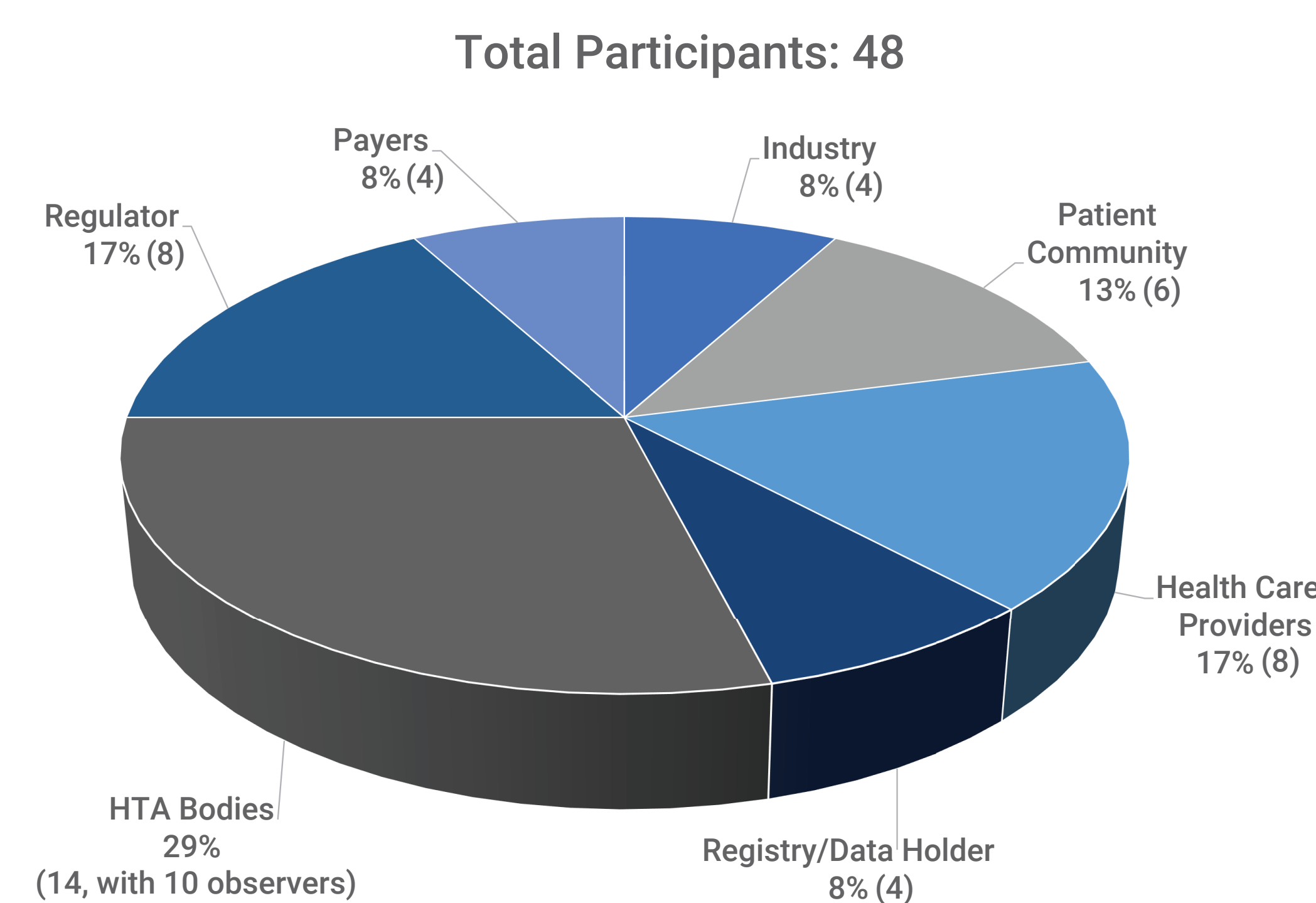
First, CADTH conducted:

- three pre-meetings, during which members of the patient community and health care providers from across Canada discussed unmet needs and challenges in the care of pLGG amongst their peers
  - two with participants from the patient community
    - nine individuals (patient group representatives, bereaved family members, and parents of children currently being treated for pediatric glioma) participated
  - one with health care providers
    - fourteen clinicians (pediatric and adult neuro-oncologists, pediatric oncologists, neurosurgeons, radiation oncologists, neuropathologists, pediatric oncology nurses, and oncology pharmacists) and 3 representatives of the POGO Networked Information System (POGONIS) participated
- two literature searches
  - a narrative review on multi-stakeholder engagement (<https://bit.ly/3SKVofA>)
  - a review of existing evidence relating to pLGG care.

On July 13, 2022, CADTH hosted a multi-stakeholder meeting to gather insights from a balanced collection of perspectives, including from members of the patient community, health care providers, registry or data holders, health technology assessment agency representatives, regulators, payers, and industry representatives. A total of 48 stakeholders attended the meeting, with representatives from each of these groups (Figure 1). A professional facilitator mediated the virtual, single-room, 3-hour multi-stakeholder meeting. During this meeting, CADTH presented key findings from the pre-meetings and the literature, and POGO staff presented on POGONIS as a potential source of RWD for pLGG. The facilitator presented semi-structured questions to engage participants in discussions about indicators and outcomes they considered important to measure.

The transcript and chat output were analyzed using methods informed by conventional qualitative content

**Figure 1: Types of Stakeholders Present at the Multi-Stakeholder Meeting**



analysis. Stakeholders had the opportunity to review the meeting summary and provide feedback.

## Results

Some key indicators discussed during the patient community pre-meetings included molecular tumour status, children’s social development, missed days of school, academic performance, body image, fertility, mental health outcomes for patients and their families, and financial burden for families. In the health care provider pre-meetings, attendees discussed the need to capture data on morbidities (e.g., blindness), radiation-free survival, secondary neoplasms, changes in treatment regimens, and side effects.

During the multi-stakeholder meeting, stakeholders discussed 3 main categories of information needs.

### Patient Characteristics

- Equity, diversity, and inclusion: socioeconomic status, ethnicity and race, geographical location, groups that are underserved
- Genetic conditions: NF1
- Molecular tumour characteristics

### Process of Care

- Treatment history
- Nursing workload: number of nursing hours required to provide treatment and care, number of hospital admissions for different treatments
- Healthcare provider administrative burden
- Prescribing data: rate of prescribing for targeted agents, safe dosage data

### Outcomes

- Financial burden for families and caregivers: out-of-pocket costs for treatment access, cost of taking time off work, how burden of cost may be modified by geographical

location, marital status, or number of other children in the family

- Long-term outcomes: follow-up longer than 5 years needed, burden of late effects
- Patient-reported outcomes
- Quality of life (QoL): assessment along treatment path, including between treatments; importance of qualitative aspect and self-reported QoL; measurable variables that may impact QoL (e.g., number of clinic visits, number of hospital/ER visits, number of hours spent in hospital, number of needles/pokes)
- Response to treatment: survival, tumour control/volume, vision, progression, toxicity, secondary neoplasms

Stakeholders identified survival, tumour control or tumour volume, and vision as hard end points. Stakeholders perceived a need for the validation and statistical analysis of data measuring patient-reported outcomes and a clear definition of disease progression. They noted the importance of consensus guidelines for response assessment (i.e., response assessment in neuro-oncology [RANO] and response assessment in pediatric neuro-oncology [RAPNO]).

## Conclusion and Next Steps

The multi-stakeholder dialogue provided important insight into measurable indicators and outcomes that stakeholders consider important for decision-making about optimizing care for pLGG. These learnings are summarized in full in a series of summary documents posted on the CADTH website (<https://bit.ly/3Dcl7Yo>) and will inform the development of a protocol using available POGONIS registry data to describe the patient population, processes of care, and outcomes for pLGG in a Canadian context.