

Factors impacting treatment decision-making in pediatric oncology: a discrete choice experiment

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Goal and Objectives

- Identify key themes in shared-decision making in pediatric oncology
- Develop a discrete choice experiment (DCE) to quantify the relative importance of factors that influence and inform pediatric oncology patient and family decision-making surrounding treatment decisions
- Understand patient/caregiver preferences resulting from the DCE to inform shared decision-making practices in the context of pediatric oncology

Methods

- Exploratory sequential mixed methods study

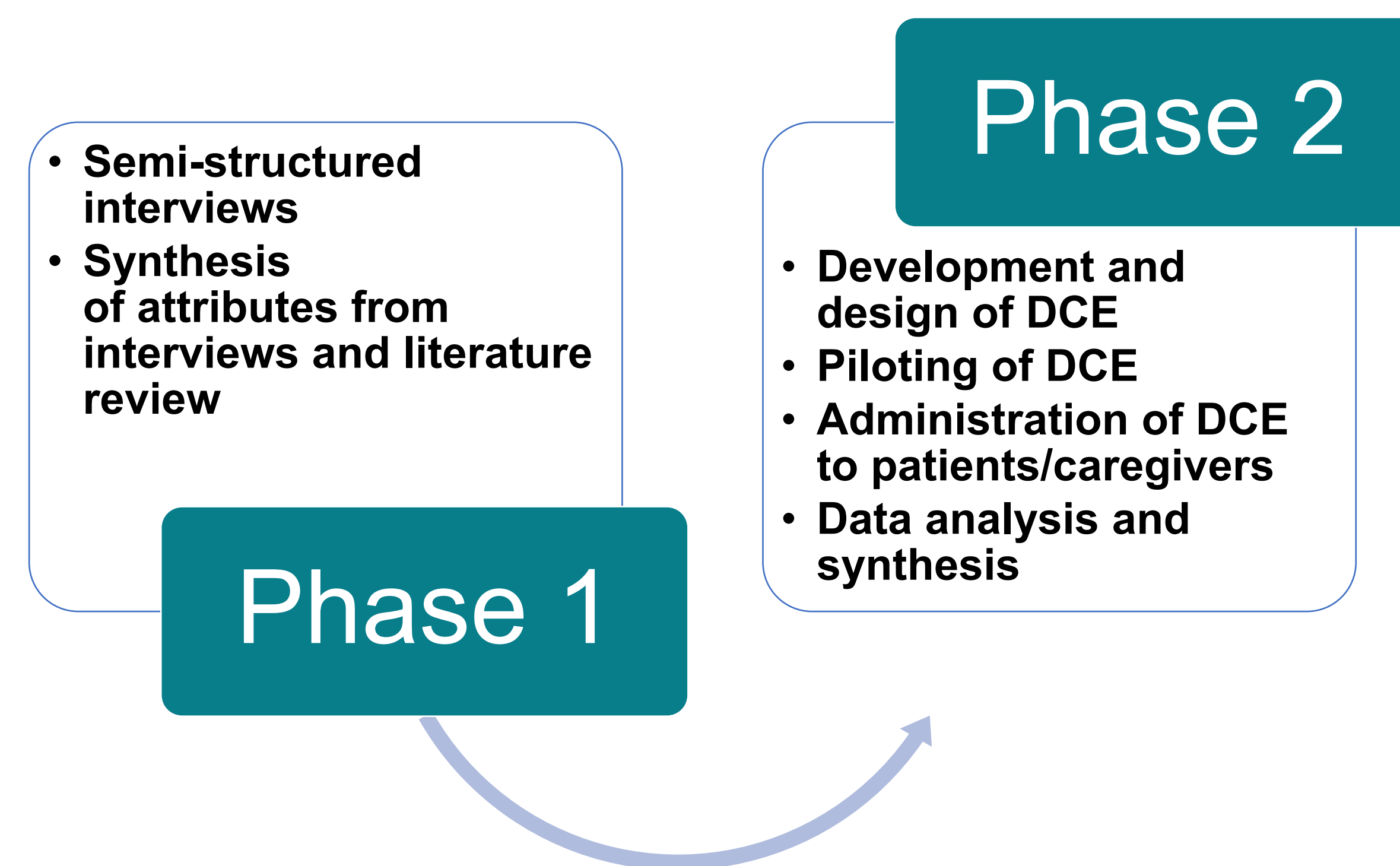


Figure 1: Phases of mixed-methods study including interviews and DCE development and administration.

Table 1: Inclusion and exclusion criteria for Phase 1 interviews

Inclusion Criteria	Exclusion Criteria
Parents/legal guardian of patients aged 0-15 years who have received or are receiving therapy for a pediatric or AYA cancer	Unable to read or speak English
Patients aged 16-29 years who have received or are receiving therapy for a pediatric or AYA cancer	Diagnosis of a non-malignant tumour
Must have received one or more of the following for their therapy: chemotherapy, surgery (for local control), radiation therapy	
Must have been diagnosed with/treated for cancer within the last 10 years	

- Phase 1 (interviews) participant recruitment
 - Purposeful sampling through Hospital for Sick Children and the ACCESS People with Lived Experience (PWLE) network
- Phase 2 (DCE) participant recruitment
 - Will be open to general public as well as patients/families affected with cancer
 - Patients and families will be approached through mailing lists, patient advocacy groups, online research communities, and the ACCESS People with Lived Experience (PWLE) network
 - General public will be approached through AskingCanadians
 - Plan for sub-group analysis of participants who have received cancer therapy, or are parents/guardians of those that have received cancer therapy for a pediatric/AYA cancer

Results

- Phase 1 actively underway with 5 interviews and literature review complete

Table 2: Participant characteristics from completed interviews

Diagnosis	Time from Cancer Diagnosis	Interviewee
Ewing sarcoma	9 years	Caregiver
Neuroblastoma	6 years	Caregiver
Anaplastic Large Cell Lymphoma	7 years	Caregiver
Osteosarcoma	3 years	Caregivers and patient
Osteosarcoma	13 years (subsequent relapses)	Patient

Clinical benefit as the priority

- "I would go broke to save her life"
- "We can't live with ourselves every day if we just let him go"
- "Get a plan together because we're not stopping"

Feeling like there is "no choice"

- "I unfortunately could not even contribute to that decision"
- "We didn't really have the foresight to or feel empowered to ask about long term side effects"

Lack of information

- "I don't feel like I was given all the information, so I made a decision not fully informed"
- "[We found] some options and reach[ed] the [other] doctors and [wrote to] them, but their answers were really late and ... she got the third recurrence, the one started spreading and we didn't have the chance to access those clinical trials"

Figure 2: Key themes identified from interviews with illustrative quotes

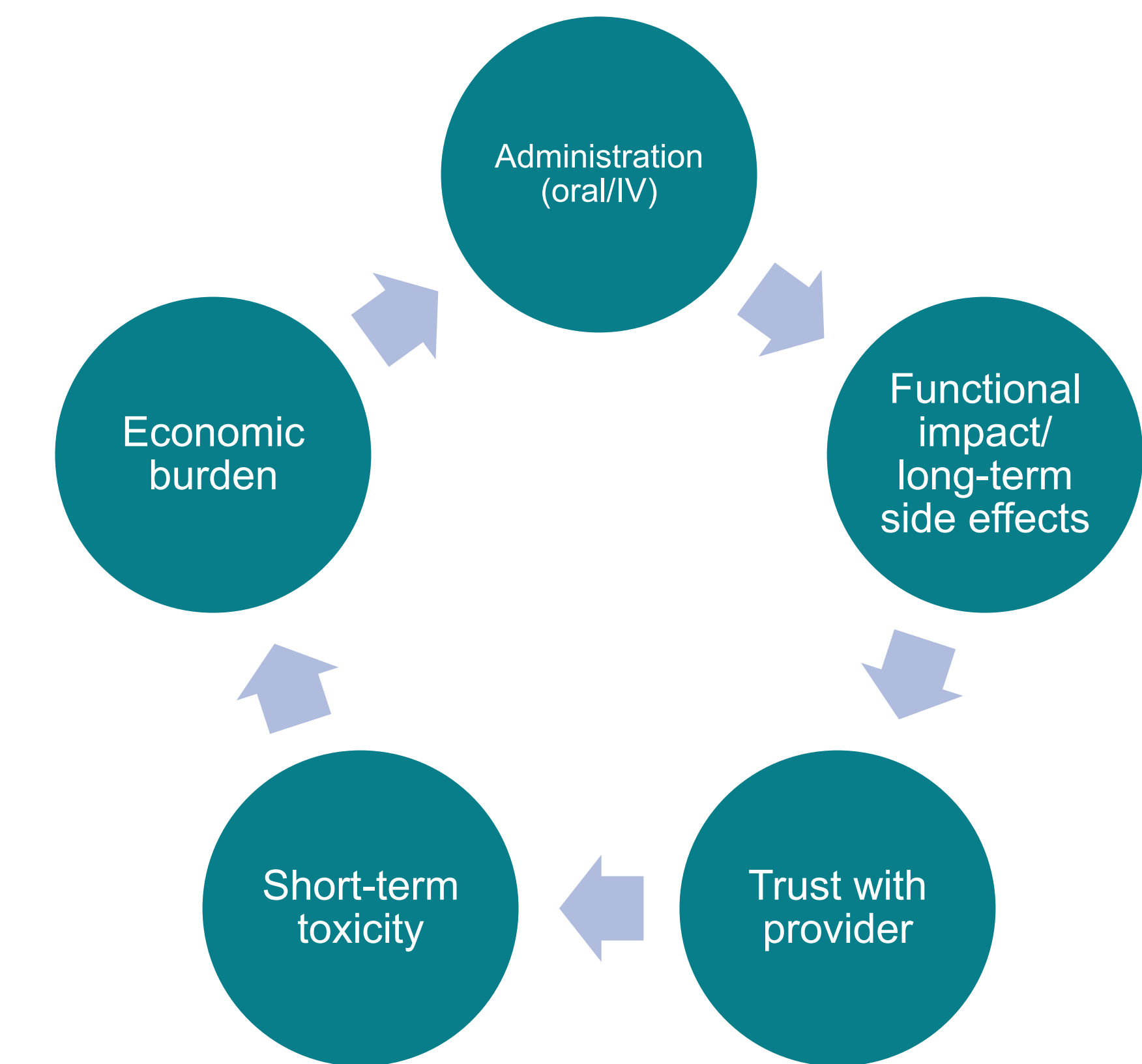


Figure 3: Candidate attributes for Phase 2 DCE, refined based on Phase 1 interviews

Impact and Outcomes

- Goal is to inform strategies and tools for effectively supporting patients in making these challenging treatment decisions with clinicians
- By enhancing shared decision-making, we hope to improve health outcomes and quality of life for these patients.
- Identify barriers to the implementation of treatment recommendations, with the potential for impactful change at the individual patient, the institutional, and health system level.

Project Timeline

- Goal to complete Phase 1 interviews by end of February
- DCE development and piloting ongoing, goal to complete by end of April
- DCE administration during Summer-Fall 2026
- DCE analysis and synthesis Fall 2026-Winter 2027
- Dissemination of results early 2027

Questions or interested in participating in interviews? Email kriti.kumar@sickkids.ca