

## Pediatric Neurology Shared Decision Making Needs Assessment

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### Introduction

- A needs assessment was conducted to collect information about opinions, attitudes and preferences of key pediatric neurology stakeholders in the context of decision making.

### Background

- Patients and families struggle to make treatment decisions, and many look to health care practitioners (HCPs) to make decisions for them. In many cases of medical decision-making, despite best efforts to reduce bias and to account for patients' values, cultural obligations and stress levels, a hierarchical paradigm continues to prevail.
- Making decisions in pediatric settings also has added complexities that cause decisions to be challenging, including the inherent dynamic of a gradually changing maturity level of the child patient, and the possibility of multiple caregivers factoring into decision making, each of whom carry their own values and treatment goals.
- A commitment to the structure of a Shared Decision Making (SDM) environment assures that factors that support decision making such as reviewing evidence, considering preferences and goals, including important others in the process and recognizing decisional stress – all help to contribute to a better health care decision.

### Purpose

- A needs assessment was done to help identify;
- what Pediatric Neurology key stakeholders and families want and/or need;
- whether existing or current programs or interventions are meeting the needs of those who are supposed to benefit;
- which patients and families need services, and;
- what might be the best alternatives for meeting those needs.

### Methodology

Questions and discussions focused on decisions, decisional conflicts, and factors contributing to decisional conflicts, knowledge, values, support, and resources.

#### 1. Interviews

Key stakeholders interviewed included five pediatric neurologists (one being new to the service area) and two clinical fellows.

#### 2. Questionnaires

One pediatric neurology nurse practitioner, two parent advisors, and one transitioned patient advisor completed questionnaires.

#### 3 Focus Groups

Four allied health staff members from the Thames Valley Children's Centre participated in a discussion using a written set of questions and topics.

#### 4. Surveys

Survey data was collected through personal interviews and discussions with the members of the Family Resource Centre, a pediatric pharmacist, London Health Sciences Centre (LHSC) hospital clergy, a pediatric social worker, and a pediatric neurology nurse.

#### 5. Archival Data

The Ottawa Framework for Shared Decision Making was reviewed: <https://decisionaid.ohri.ca>

### Current State/Where We Are Now

#### Health Care Professionals Feedback

- health care professionals (HCP) identified a number of medical decisional conflicts deficits in knowledge, expectations, and resources needed to support their work.
- decisional conflicts focused primarily on medical interventions such as treatment choices, medications, and surgeries
- what hinders the decision making are those who are not realistic, or listening, or hearing the information due to their own learning disabilities or mental health and emotional issues
- poor knowledge about the disease
- conflicting opinions
- pressure from others
- families seeking second opinions
- perceived loss of function
- inability to accept diagnosis
- refusal of family to consider the options presented
- profound cultural differences and beliefs

#### Patient and Family Advisors Feedback

- patients and parents focused primarily on the need for social supports and educational resources needed from HCPs to assist them with their journey such as knowledge of various therapies, use of medications and their side effects
- how they can best support themselves and their child when at times the diagnosis is too much
- trying to understand how the diagnoses implicates the patient and family immediately, as well as, throughout the duration of their life
- how to cater the everyday decisions to long term implications
- families need overall support throughout the journey
- knowledge of ongoing research
- easier to make decisions in a supportive dynamic environment
- need increase support at times of transition or typical milestones that are not being reached example: school, driving, dating etc.
- families found decisions challenging when you are in an environment that you feel you may be judged

### Future State (Where We Want To Be)

The future state identified shared decision making strategies by both HCPs and families that can be developed to meet their needs, both in a general and specific way.

#### Health Care Professionals Future State

- informed value based decisions
- accessible on line tool box for HCP's and families
- engaged and knowledgeable HCP's on SDM
- inventory of pediatric evidence based decision aids
- a recognized Children's Hospital patient endorsed service
- smoother transition to timely & challenging decision making for families of pediatric patients
- trusting environment with less barriers and reduced decisional regret
- needed resources to support families
- dedicated multidisciplinary clinics
- well established and functioning SDM
- pediatric culture and environment

#### Patient and Family Future State

- patient centered care environment
- a template for families to guide them through the decision making process that would include: topic of decision, what they know about topic, possible outcomes, what they do not know, who they need to talk to, find out more, what are your questions, and follow up discussion, reliable info to share with family and friends supporting decisions
- no judgment

### GAPS

Gaps, or needs, are defined as what is and what should be; from this perspective, it is important to understand what is already being done and how well it meets the needs of the families and practitioners.

HCP's identified a lack of dedicated resources (i.e. neurology nurse educator, social worker, educational aids, and a well-defined shared decision making environment) as barriers to supporting decision making and time needed to support families. HCP's identified a lack of mutual trust as core for decision making.

Patients and families echoed the same barriers as HCP's and, identified the need to have more time devoted to them during clinic visits to have a better understanding of their children's social development and future treatment plans.

### Strengths and Limitations

A large number of archival data sources were available

Key stakeholders willingly participated

Parent Advisors and transitioned patients were thankful for the opportunity to participate

Key stakeholders were limited to pediatric neurology

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### Reference:

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### Websites:

<https://decisionaid.ohri.ca/>  
<https://www.cincinnatichildrens.org/service/janderson-center/evidence-based-care/decision-aids>  
[http://med.dartmouth-hitchcock.org/csdm\\_toolkits.html](http://med.dartmouth-hitchcock.org/csdm_toolkits.html)

