

# Research Priorities for Children with Neurological Impairment and Medical Complexity in High-Income Countries

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## For which topic were research priorities identified?

children with neurological impairment and medical complexity

## In which location was the research priority setting conducted?

North America - Canada; North America - USA; Europe - Ireland; Europe - United Kingdom; Australia - Australia; South America - Chile; Europe - Netherlands; Asia - Hong Kong; Europe - Spain

## Why was it conducted at all?

Unfortunately, less attention has been given to establishing the evidence base to guide clinical care practice for children with neurological impairment and medical complexity. Evidence for diagnosing or treating common clinical scenarios for children with neurological impairment and medical complexity often relies on extrapolation from studies conducted on otherwise typically developing children. Exclusion of children with neurological impairment and medical complexity from guidelines and clinical pathways creates knowledge gaps that limit evidence-based clinical practice. Furthering clinical research focused on children with neurological impairment and medical complexity supports improvements in their care and outcomes. The consensus of clinicians and patients/caregivers is an increasingly important element of the research agenda setting and can produce more relevant agendas while simultaneously reducing research waste.

## What was the objective?

to develop a list of the top priorities for clinical research, clinical topics, and specific research questions in the care of children with neurological impairment and medical complexity, reflecting the prioritization of an international expert panel consisting of both clinicians and family care givers

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

November 2019 - June 2020

## Which methods were used to identify research priorities?

Delphi

## How were the priorities for research identified exactly?

Step 1: steering committee defined the scope of the study. Step 2: Delphi round 1: surveys separately for clinicians and family caregivers, participants were asked to suggest priority research areas, clinical topics, and specific questions relating to the clinical care of children with neurological impairment and medical complexity, 601 individual comments or questions were submitted, the raw suggestions spanned 73 clinical topic areas. Step 3: data analysis: suggestions were reviewed, refined and re-formulated into PICO format, topics that could not be developed into specific research questions by the steering committee were excluded, this resulted in 26 clinical topics and 126 questions. Step 4: Delphi round 2: family caregivers and clinical experts participated in round 2a, participants were asked to rate importance of each clinical topic from the perspective of future research, round 2b asked clinical experts to select up to seven most important clinical topics and to rate each research question based on their importance to clinical care and the current state of available evidence, resulting in 49 clinical questions along 9 clinical topics. Step 5: Delphi round 3: clinical experts were asked to rate the importance of research questions based on their importance to clinical care and the current state of available evidence

## Which stakeholders took part?

Delphi round 1: 49 clinicians and 12 caregivers. Delphi round 2a: 43 clinicians, 6 caregivers. Delphi round 2b: 43 clinicians. Delphi round 3: 41 clinicians.

## How were stakeholders recruited?

The steering committee nominated a range of international clinical experts who provide clinical care to children with neurological impairment and medical complexity. Recruitment was limited to physicians and nurse practitioners. Family caregivers of children with neurological impairment and medical complexity were recruited using social media feeds.

## Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of an advisory board and a steering group. The steering group was composed of clinician-researchers from Ireland (n=1), Canada (n=4), and the USA (n=4), a parent of a child with neurological impairment and medical complexity. The advisory board was composed of the Research Family Advisory and Complex Care Family Advisory committees at the primary academic center and consisted of 14 members.



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