Improving health care delivery for children diagnosed with rare metabolic diseases by learning from families and providers: Protocol for Phase I, a prospective, mixed methods cohort study of families’ health care experiences


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**Phase I: METHODS**

**Engagement of families**

**Engagement of families is pivotal for this project’s focus on family experiences.** FAMILIES will co-design an intervention that will emerge from this study. 3-4 investigators will pilot test data collection with families of children with IMD to assess the feasibility of data collection approaches and implementation. Larger numbers of patient/family advisors (~10) from diverse backgrounds and experiences will advise on data collection tools and planned questions.

**Data collection**

- **WHO are the health care providers involved in care?**
- **WHAT is the health care experience like, from the families’ perspective?**
- **WHAT is the impact of very positive and very negative health care experiences?**

**Phase 1 goal:** To develop and pre-test data collection tools to identify potential eligible participants, to design and test of intervention, and to develop and test metrics for intervention evaluation.

**Phase 1 key questions:**

- **Who are the health care providers involved in care?**
- **How are care providers connected to each other and to the family?**
- **WHAT is the health care experience like, from the families’ perspective?**
- **WHAT is the impact of very positive and very negative health care experiences?**

**Study phases**

**Phase 1**

- **Describe the health care experiences of children with IMD (families’ perspectives)**
- **Understand the barriers and facilitators of effective care delivery across the system (providers’ perspectives)**
- **Conduct a rapid review of existing strategies recommended for family-centered care for children with chronic diseases**
- **Engage families & providers to co-design interventions to improve care (logic models & experimental evaluation plans)**

**Phase 2**

- **Develop new, evidence-based tools and approaches to improve care delivery for children with IMD**
- **Conduct a prospective, mixed methods cohort study of families’ health care experiences**

**Phase 3**

- **Develop new, evidence-based tools and approaches to improve care delivery for children with IMD**
- **Conduct a prospective, mixed methods cohort study of families’ health care experiences**

**Phase 4**

- **Develop new, evidence-based tools and approaches to improve care delivery for children with IMD**
- **Conduct a prospective, mixed methods cohort study of families’ health care experiences**

**References**