

## Caring for patients with metabolic disorders from newborn screen to year one: Provider workload, workflow, and issues for the medical genetics workforce

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**Purpose:** To explore issues and barriers to providing treatment for children who screen positive for a metabolic condition upon newborn screening (NBS), and to describe medical genetics providers' perceptions of expansions to the NBS panel and its impact on the workforce.

**Methods:** In-depth interviews were conducted with metabolic care providers (clinical geneticists, nutritionists, genetic counselors, etc.) in New England concerning the care provided to newborns who screened positive for a metabolic condition on NBS, through the first year of life.

**Results:** Care coordination was fragmented for many conditions and roles of providers were often unclear. Providers spent a large amount of time educating families and other providers. While enhanced NBS panel requirements were viewed as promising, there were concerns about workload and follow-up time related to treatment.

**Conclusion:** To improve the care provided to patients diagnosed with metabolic conditions and the work responsibilities of metabolic providers, care coordination, practice guidelines, and education needs should be addressed.

### Biography

Robert J. McGrath completed his Ph.D. at Brandeis University and received his Masters of Science in Health Policy and Management from the Harvard University School of Public Health. He is the chair of the Department of Health Management and Policy at the University of New Hampshire and former director the New Hampshire Health Information Center. He has published in numerous impactful journals and presented nationally on issues related to genetic and genomic workforce for children with metabolic conditions and special health needs.

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