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Long Term Follow Up In State Newborn Screening Programs: A Multi-method Analysis

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Background

Since the 1960's newborn screening has been an essential part of state public health efforts. The largest population-based screening program in the US, newborn screening identifies genetic and metabolic disorders which can have severe consequences without early detection and treatment. Long-term follow-up (LTFU) of individuals diagnosed through newborn screening involves quality assurance, evaluation, and monitoring of patient treatment and outcomes.

Objectives

Assess policies, perceptions, and practices of state newborn screening (NBS) programs in regard to long-term follow-up. Identify best practices and barriers to NBS programs engaging in effective LTFU, in order to inform the development of national guidelines or policies.

Methods

A multi-method approach was used that included interviews, focus groups, and an online survey. Forty out of fifty state NBS programs participated. Qualitative data was categorized using grounded theory and content analysis. Complex adaptive systems theory was the conceptual lens for interpretation of the data.

Findings

The majority of NBS programs currently do no LTFU. In those that do, there is great variability in policies, practices, and capacity. Major findings include (a) the need for state NBS programs to further develop their relationships with private providers and public programs; (b) cultural and staffing realities that undermine consistent LTFU activities; (c) the need for standardization of data collection and analysis methods across states; and (d) the reliance of NBS programs on relationships and practices that hinder the development of more systematic approaches to LTFU.