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Original Communication

Incomplete Follow-up of Hemoglobinopathy Carriers Identified by Newborn Screening Despite Reporting in Electronic Medical Records

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Abstract

Objective

Has the recent availability of newborn hemoglobinopathy screening results within patient electronic medical records (EMR) of birth hospitals facilitated follow-up by primary care pediatric providers?

Methods

An online survey of all 137 primary care pediatric providers at a New York City academic medical center was conducted in 2008–2009 to assess practices for hemoglobinopathy trait follow-up. Physicians were resurveyed 1 year later, following educational outreach and a letter of instruction underscoring the availability of screening results in the EMR. All 62 primary care pediatricians were surveyed at a nearby city hospital for comparison.

Results

Overall response rate for the initial survey at the teaching hospital was 58% for pediatricians (N = 57) and family physicians (N = 23), and 50% for pediatricians at the city hospital (N = 31). Despite high prevalence of hemoglobinopathies in the population served and screening results in EMRs, only 46.2% of providers surveyed at the academic center reported routinely checking results of their infant patients: 38.6% of pediatricians and 66.7% of family practitioners. Some respondents were unaware that results are available in the EMR. The proportion of providers checking screening results was not significantly affected by educational intervention (N = 40). Provision of recommended follow-up for a positive trait result was modestly improved, especially in referring families for genetic counseling (25% to 50%, $p < .01$). In contrast, most pediatricians (83%) at the city hospital routinely check and perform follow-up.

Conclusion

Despite access to results in the EMR and targeted educational outreach, follow-up of hemoglobinopathy screening by primary care varies widely across clinical sites.

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Keywords

infant health; screening; sickle cell disease; electronic medical record

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