

Reduce Disparity of NBS Laboratory Services in the Heartland Region

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INTRODUCTION

- Screening of all newborns for congenital and inherited disorders is a vital public health service.
- Historically each test was used to detect one disorder and the test was generally inexpensive and technologically simple.
- Traditionally this allowed each state to take full responsibility for NBS using resources contained within their state.
- This autonomy resulted in a wide variety of structures and performance standards.
- Recent advances in technology, lobbying, and national recommendations for a more uniform screening system has challenged this model.
- Competition for limited resources has made it difficult for states, especially rural states, to fully meet these new expectations.

HYPOTHESIS

Providing a forum where information can be shared, opportunities for improvement in the quality of and access to NBS services can be identified, and strategies for identified improvements can be developed will have significant impact on enhancing NBS services within the Heartland region.

SPECIFIC AIM

Provide a forum where synergy can develop among the Heartland NBS laboratories and opportunities for cooperation between states can be cultivated and lead to enhancements in newborn screening services within the Heartland region.

METHODS

- Develop and distribute a survey to all Heartland state NBS programs to identify areas of need or issues of interest.
- Use the results of the survey to develop an agenda and convene a two-day workshop at the new Iowa Labs Facility in Ankeny, Iowa.
- Two representatives from each Heartland state will be invited (expenses paid) and open to others.
- Facilitators will be used to help identify areas of priority, available resources, specific projects, develop action plans and timelines.
- Monthly teleconferences for project teams to monitor and ensure progress.
- Hold one-day meeting in Iowa for final assessment of projects, identify continuation projects, funding needs, and publication opportunities.

PROGRESS TO DATE

- Project has not yet been started.