

Pilot Testing Public Health Surveillance Case Definitions for Newborn Screening

In December 2012, NewSTEPS conducted a 3 month pilot study of the case definitions with ten state Newborn Screening (NBS) programs. Pilot test states were provided a series of training webinars and a tool kit that included the draft case definitions, case definition tables, and a sample letter to medical providers that described the purpose of the case definition pilot project.

Results of the Pilot Study

- At the end of the pilot study, several state NBS programs that participated did not have established relationships with the medical providers in their state and the pilot project helped to build this relationship.
- NewSTEPS data repository can now collect information on state NBS programs to be used for quality assurance and improvement. The data repository incorporates the case definitions and includes an automated algorithm to classify cases based on certainty of diagnosis.

Lessons Learned by Pilot States

- It is important to establish a good relationship with each medical provider and to provide them with all the relevant information ahead of time
 - Having a description and purpose of the case definitions helped state NBS programs provide information to the medical providers
 - The introductory letter and case definition worksheets were very helpful in showing exactly what information was needed
- The information being asked for is not all or nothing. Whatever information can be provided is useful. As more information on a case is made available, the information can be updated in real time within the NewSTEPS data repository