

## Newborn Screening: A National Snapshot with Implications for Emergency Preparedness

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**Objective** To conduct a nationwide survey of the methods used in newborn screening (NBS) programs to notify birthing centers, pediatricians, and parents of the results of NBS tests in every state and territory.

**Study design** State and territory NBS program representatives were identified and contacted via e-mail. Each state or territory responded to a survey asking questions about their methods (eg, telephone, e-mail, surface mail) for reporting normal, borderline, and abnormal results.

**Results** With 100% of states and territories responding, a broad array of reporting methods were identified with substantial variability between states for delivering NBS test results to the responsible entities. Mail, telephone, and facsimile were the predominant reporting methods. The majority of states and territories did not have Web-based reporting methods.

**Conclusions** State-to-state variability complicates NBS laboratory backup in the event of catastrophic failure and makes emergency preparedness difficult. The most common reporting methods (surface mail, telephone) do not account for likely interruption of infrastructure and the urgent need for abnormal result reporting for patients evacuating their community. Harmonization between states in their reporting methods via Web-based methods should be developed. (*J Pediatr* 2013;162:955-7).

Newborn screening (NBS) program policies are typically based on individual state or territorial mandates with support provided by the federal government. Information is not currently available about how health care providers access NBS results and to whom NBS results are reported. Each state chooses reporting methodologies independently and no national guidelines exist on NBS results reporting. For harmonization between states, which may provide backup support to each other during an emergency, the listing of various reporting methods and a policy on ideal methods are necessary.<sup>1-3</sup>

This study grew from an emergency preparedness tabletop exercise conducted by the Southeast NBS and Genetics Regional Collaborative (SERC) Emergency Preparedness Workgroup in July 2009. The Emergency Preparedness Workgroup is a core grant activity of the SERC, a Health Resources and Services Administration–funded activity, and developed from interest initiated by the network's responses to hurricanes Katrina and Rita.<sup>4,5</sup> The Emergency Preparedness Workgroup recognized that NBS programs across the country access laboratory results and approach notification of potentially impacted infants' parents and care givers using different methods.<sup>6</sup> Of particular concern was how these variations in reporting methods could prove detrimental to connecting infants with presumptive positive results and with a skilled caregiver, especially during and after an emergency requiring evacuation of the patients' home or even city.

Normal NBS results generally terminate further evaluation within the network, but borderline results require resampling and rescreening (an additional interaction between the health care system and patient), and abnormal results trigger referral to health care specialists. Contacting patients to deliver results can be difficult in nonemergency situations. Emergencies complicate communications of normal results but introduce special challenges by required repeat interaction for borderline and abnormal results.

We conducted an assessment of how the 53 states and territories communicate NBS results. The goal was to assess how physicians and patients access NBS results in routine, nonemergency situations in each state or territory by inventory of current NBS reporting methods. We compared the various methodologies for all types of NBS results and hoped to identify ideal reporting methods, which could be proposed as uniform guidelines.

### Methods

A Web-based survey was developed and distributed to the NBS laboratory and NBS follow-up representative in each state and territory. Several NBS professionals from outside the SERC region reviewed the survey for clarity and intent

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NBS	Newborn screening
SERC	Southeast NBS and Genetics Regional Collaborative

before use. State and territory representatives were identified through the National Newborn Screening and Genetic Resource Center Web site<sup>7</sup> (eg, “NBS laboratory state representative”; “NBS follow-up state representative”). In some cases, the individual identified himself or herself as “both.” Initial contacts were e-mailed with a survey Web link ([www.surveymonkey.com](http://www.surveymonkey.com)). Data were tallied electronically and manual data modifications and additions continued through 2011 as responses became available. E-mails were sent to all respondents in February 2011 after the data were tallied to verify accuracy of their responses.

The survey focused on 2 sets of questions: (1) “To whom are NBS results reported?” (2) “What methods are used to do this?” These questions were asked for each of the following types of results: “normal,” “borderline,” and “abnormal.” Regarding the entity to whom results were sent, the potential responses were submitting entity, primary care provider, specialist (meaning genetics health care network), follow-up coordinator (state NBS follow-up coordinator), family, and other (open field response). Regarding the method of reporting NBS results, the potential responses were via Web, facsimile, mail, telephone (nonautomated), telephone (automated), and other. In each case, respondents were instructed to select as many responses as appropriate. A final question asked respondents, “What is your preferred method for reporting abnormal results?” In a few cases when 2 respondents (follow-up and laboratory representatives) within 1 state or territory gave varying responses, both responses were included; each state or territory had a chance to review and revise the response in the follow-up e-mail.

## Results

Of 106 possible responses, there were a total of 79 replies. Of the 79 replies, data were submitted from each of the 53 states or territories, for a response rate of 100%. Twenty-six of 79 (33%) respondents identified themselves as a representative of the NBS laboratory, 34 (43%) as a representative of NBS follow-up, and 19 (24%) as both.

Responses to the question “How were results communicated?” yielded a wide range of responses (Table I; available at [www.jpeds.com](http://www.jpeds.com)). Results indicate more than one method of communicating results (“normal,” “borderline,” or

“abnormal”), but trends are evident and relate to the type of result to be reported. For normal results, mail and facsimile were the most common means of communicating NBS results. For abnormal results, nonautomated telephone and facsimile were the most common means of communicating results. Other methods of communication reported included in-house database access, secure e-mail, and local networks but were primarily internal NBS system communications. Only 40% of states and territories reported their abnormal results using Web-based/online access.

Responses to the question “To whom were results communicated?” yielded a range of responses (Table II). In the majority of cases, the submitting entity, primary care physician, the specialist, and the follow-up coordinator were contacted in several ways; rarely, the family was contacted. In general, the formula for selecting who is contacted is dependent on whether the result is normal, borderline, or abnormal, and therefore represents the urgency of the results. For abnormal results, all except 4 states/territories communicated results to both the submitting entity and the primary care physician or specialist. In a few states, midwives, along with the state and/or county health department, are contacted with the results.

When asked the preferred method for reporting abnormal results, the most common response was “nonautomated telephone call.”

## Discussion

This is a national snapshot of NBS results reporting across all states and territories. A wide range of reporting methods and practices are in evidence. The American College of Medical Genetics, the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, the Health Resource and Service Administration, and the Centers for Disease Control and Prevention promote NBS harmonization across the country through the NBS Saves Lives Act of 2008 and the NBS Contingency Plan.<sup>8,9</sup> NBS reporting practices are a critical piece of harmonization as states and territories develop emergency preparedness backup plans with other states,<sup>1-3</sup> and these results may guide such efforts. Although many priorities exist for injured and displaced populations during an emergency, infants with treatable inherited metabolic diseases offer opportunities for preventable morbidity and mortality.

As NBS programs develop emergency preparedness, communications methods that use differing infrastructure are preferable to reliance on any single method. Currently, most states use more than one reporting method. But the favored methods by the survey respondents—mail, nonautomated and automated telephone, and facsimile—rely on intact land-based telephone infrastructure and hand delivery, methods that are easily overwhelmed or disabled in emergencies. The preferred method of reporting by respondents in this survey was nonautomated telephone call, a marginally useful method during a major emergency.

Delivering presumptively positive NBS results to families who evacuate a community due to emergency is difficult

**Table II.** Summary of the methods of reporting normal, borderline, and abnormal results

Communication method	NBS result, No.		
	Normal (n = 53)	Borderline (n = 52)	Abnormal (n = 53)
Mail	49 (92%)	43 (83%)	44 (83%)
Telephone	17 (32%)	36 (69%)	47 (89%)
Facsimile	35 (66%)	38 (73%)	46 (87%)
Web/online	20 (38%)	19 (37%)	21 (40%)
Automated telephone	6 (11%)	7 (13%)	7 (13%)
Other	9 (17%)	10 (19%)	15 (28%)

Note: % represents percentage of all states and territories (N = 53). “Other” category included laboratory information systems. South Carolina does not report “borderline” NBS category.

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