Welcome to the California Newborn Screening Hospital Survey

Thank you for participating in our brief Newborn Screening (NBS) survey. The goal of this survey is to help our NBS program in California better understand the hospitals' NBS processes so that together we can improve the timeliness of newborn screening. Newborn screening began 50 years ago and has evolved over the years and currently, the California Department of Public Health NBS Program screens babies for 80 disorders.

In February, new federal guidelines were approved that recommend that NBS blood spots are collected no later than 48 hours and the blood spots are received by the NBS lab within 24 hours of collection. In order for California to meet these goals, we will be working with all birth facilities across our state to improve the NBS process from collection of the blood spots to completion and reporting of results. Your feedback is very important to us. Together, we can ensure that the babies of California are healthy and safe. Thank you for your time, please complete the survey before Thursday, June 18, 2015.

* 1. What is the name of the hospital that you represent/work for?

2. What is your hospital's 4 character facility code? (R or K followed by 3 digits; or PX followed by 2 digits).

* 3. Who is responsible for collecting NBS blood spots in the Regular nursery/Rooming In/Mother-Baby unit at your facility?
   - Nursery nurse
   - Lab staff
   - Both nurses and lab staff
   - I don't know

* 4. Who is responsible for collecting NBS blood spots in the NICU at your facility?
   - NICU nurses
   - Lab staff
   - Both nurses and lab staff
   - I don't know
   - n/a - we don't have a NICU
5. Who is responsible for filling out the information on the NBS blood spot card?
- Nursery/NICU nurses
- Lab staff
- Unit clerk/Administrative staff
- I don't know
- Other (please specify)

6. For infants in the Regular Nursery, Postpartum, Couplet Care, Rooming In etc. What is your average time for Collecting the NBS blood spot?

<table>
<thead>
<tr>
<th>Time Range</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 to 24 hours</td>
<td></td>
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<tr>
<td>24 to 36 hours</td>
<td></td>
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<tr>
<td>36 to 48 hours</td>
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<tr>
<td>48 to 72 hours</td>
<td></td>
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<tr>
<td>Just prior to discharge</td>
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</tbody>
</table>

Select the Most Frequent Occurance

7. For infants in the NICU, what is your average time for Collection of the NBS blood spot

<table>
<thead>
<tr>
<th>Time Range</th>
<th>Options</th>
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<tbody>
<tr>
<td>less than 12 hours</td>
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<tr>
<td>12 - 24 hours</td>
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<tr>
<td>24-36 hours</td>
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<td>36 to 48 hours</td>
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<tr>
<td>48 to 72 hours</td>
<td></td>
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<tr>
<td>greater than 72 hours</td>
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</tbody>
</table>

Select the Most Frequent Occurance
8. On average, how long does the following NBS blood spot process take at your facility?

<table>
<thead>
<tr>
<th>Average Drying duration from collection to packaging</th>
<th>&lt;3 hours</th>
<th>3-4 hours</th>
<th>5-8 hours</th>
<th>8-12 hours</th>
<th>12-24 hours</th>
<th>&gt;24 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>○</td>
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</tbody>
</table>

Average drying duration from collection to packaging:

9. Does your hospital's out-patient laboratory collect NBS blood spots (upon request) post discharge?
   ○ Yes
   ○ No

10. What is your hospital's primary mode for delivery of NBS blood spots to the NAPS/Regional lab (check all that apply?)
   - Golden State Overnight (GSO)
   - Hospital courier
   - Fed Ex Overnight
   - USPS Express Overnight
   - UPS Next Day Air
   - Other (please specify)
11. If utilizing another delivery mode other than GSO, please specify why (check all that apply).
- Did not know GSO was available
- Alternate mode of delivery is faster
- Alternate mode of delivery is more reliable
- Alternate mode of delivery is easier
- Other (please comment)

* 12. If GSO Saturday specimen pick-up is available free of charge in your area, what challenges, if any, does your hospital face in utilizing it?
- No challenges
- Saturday pick-ups are challenging (see comment)

* 13. Optimally, California NBS Program recommends NBS blood spots be received within 24 hours of collection at the NAPS/Regional Lab. Do you have tools and resources to meet this goal?
- Yes
- No
- I don't know

14. What tools and resources are needed to reach the goal that NBS blood spots are received within 24 hours of collection at the NAPS/Regional Lab? (check all that apply).
- Additional Training
- Best practice reference guide
- Alternate courier service
- Other (please specify)
15. The California NBS Program issues quarterly HEPP reports to each hospital to report the hospital's performance regarding NBS blood spot forms completion, unsatisfactory specimens, timing of collection, and transit time. Do you or your hospital staff use these quarterly reports for quality improvement?
- Yes, the report is shared with lab and/or nursing staff
- Yes, I am aware of the report but I've never used it for quality improvement.
- Yes, but the data is difficult to interpret
- No, I did not know quarterly HEPP performance reports were provided.

16. CDPH provides educational booklets entitled Important Information for Parents about the Newborn Screening Test (IIP) to all California birthing facilities. Is your hospital using these educational tools?
- Yes, the IIP booklets are distributed to OB patients on admission.
- Yes, the IIP booklets are distributed to OB patients after delivery.
- Yes, but I don't know how they are distributed.
- No, I am not aware of the NBS IIP booklets.
- No, but our hospital is interested in receiving IIP booklets.
- Other, please specify

17. Please provide contact information for further correspondence with the CDPH Newborn Screening Program
* Contact Person's Name
* Hospital Name
* Hospital Mailing Address
* City/Town
* ZIP/Postal Code
County
* Email address
* Phone
Fax
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. What is your preferred method to receive written communication</td>
<td>Email, Fax, Mail</td>
</tr>
<tr>
<td>regarding changes and updates for the California NBS Program?</td>
<td></td>
</tr>
<tr>
<td>19. Please provide any additional comments regarding NBS in California.</td>
<td>Comment below</td>
</tr>
</tbody>
</table>

Thank you for taking the time to complete this survey.  
CDPH Genetic Disease Screening Program  
850 Marina Bay Parkway, F175 Richmond, CA  94804