

# Primary Care Provider (PCP) Response to Borderline and Invalid NBS Results

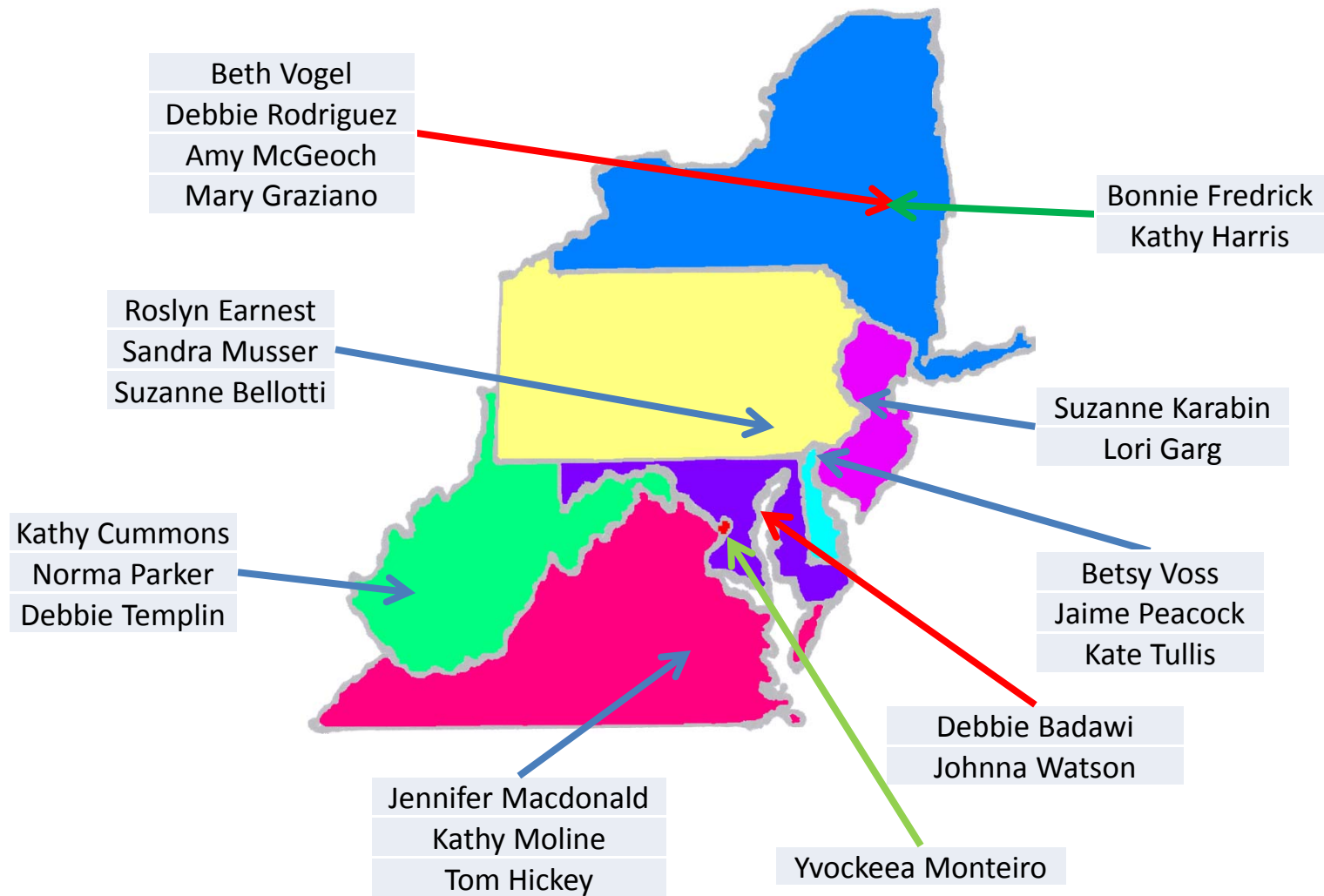
Katharine B. Harris, MBA, NYMAC  
Project Manager, representing

NYMAC NBS Follow-up  
Interest Group



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## NYMAC Follow-up Interest Group

- Formed in June 2012 at the NYMAC SCID/LSD Symposium
- Conference calls
- Meeting in Albany November 2012 to develop this project

### Question:

Do PCPs fully understand NBS results and their implications?

### Narrower question:

Do PCPs respond appropriately to NBS results of “Invalid” and “Borderline”?



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### Proposed 3-part Study

1. Study the current PCP response to NBS results of “invalid” and “borderline”
2. Execute an educational campaign
3. Repeat the study

Six states participated in this study: DE, MD, NJ, NY, VA, WV

Generally speaking PCP offices are responsible for responses to invalid and borderline NBS results

By the time these results are available, the healthy newborn has been discharged from the hospital or birthing center



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## Data from July 1 – September 30, 2012

- Number of specimens received
- Number of specimens determined to be “invalid”
- Number of specimens determined to be “borderline”
  - Excluded newborns who are in the NICU – they are still in the care of hospitalists and not the PCP



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# Data Points

- Date the PCP received borderline or invalid results
  - Notification is generally by phone, with follow-up by fax or mail; at least one state only mails borderline notification
- Date the second specimen was collected

## Specimens Received by NBS Laboratories

July 1 - September 30, 2012

	Total specimens	# Invalid	% Invalid
Delaware	4,585	9	0.20%
Maryland	21,339	139	0.65%
New Jersey	31,174	270	0.87%
New York	68,785	842	1.22%
Virginia	25,970	83	0.32%
West Virginia (48 hr. cut-off)	7,628	1,355	17.76%
<b>Total</b>	<b>159,481</b>	<b>2,698</b>	<b>1.69%</b>



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## Invalids

- 23% (range 1% - 39%) collected on the day of notification
- 55% (range 31% - 77%) collected within a week
- 71% (range 57% - 89%) collected within 2 weeks
- 86% (range 76% - 100%) collected within 30 days

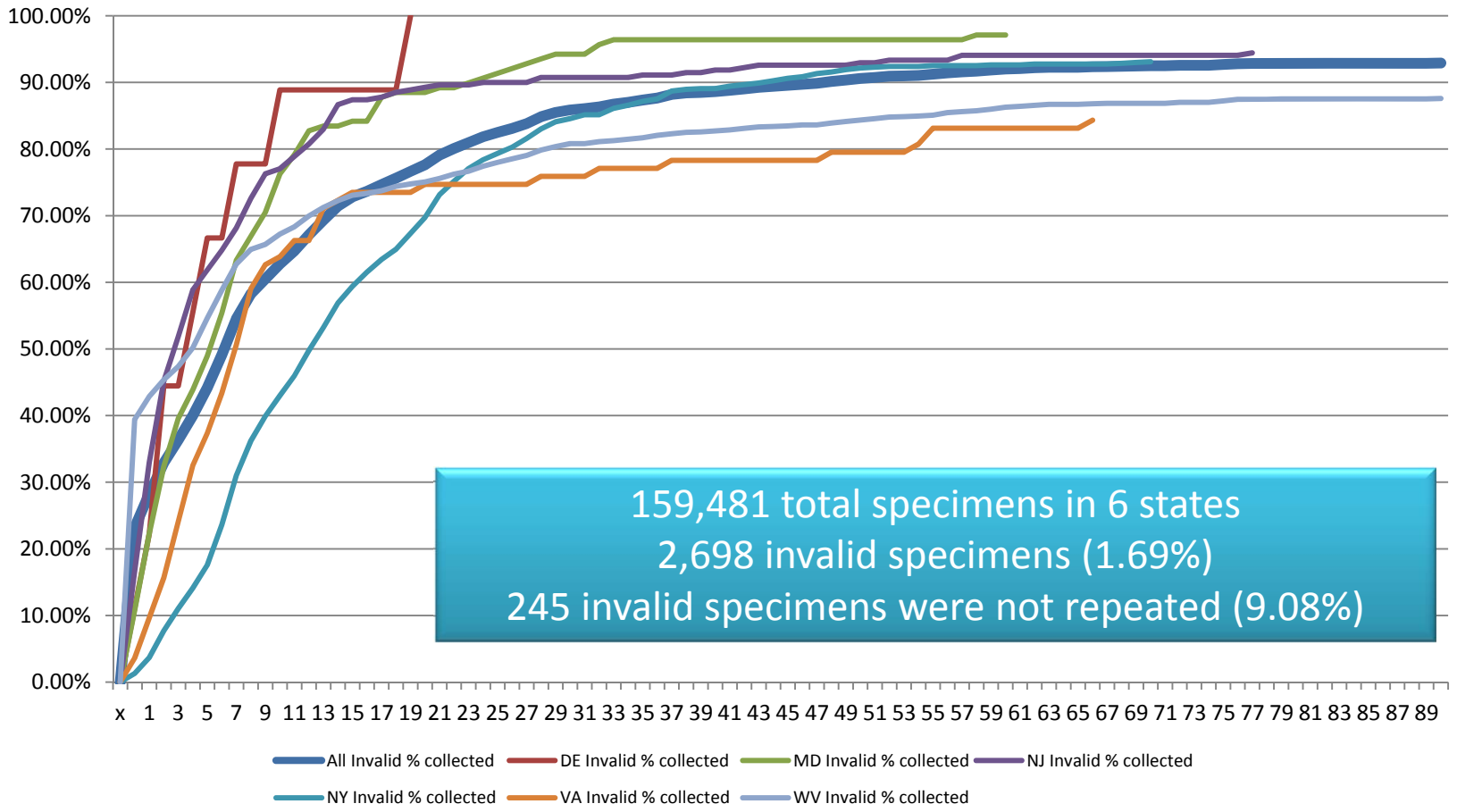


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## Invalid Data For All States and Combined



159,481 total specimens in 6 states  
 2,698 invalid specimens (1.69%)  
 245 invalid specimens were not repeated (9.08%)



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## Specimens Received by NBS Laboratories

July 1 - September 30, 2012

	Total specimens	# Borderline	% Borderline
Delaware	No borderline category		
Maryland	21,339	58	0.27%
New Jersey	31,174	119	0.38%
New York	68,785	165	0.24%
Virginia	25,970	304	1.17%
West Virginia	7,628	507	6.65%
Total	154,896	1,153	0.74%



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## Borderlines

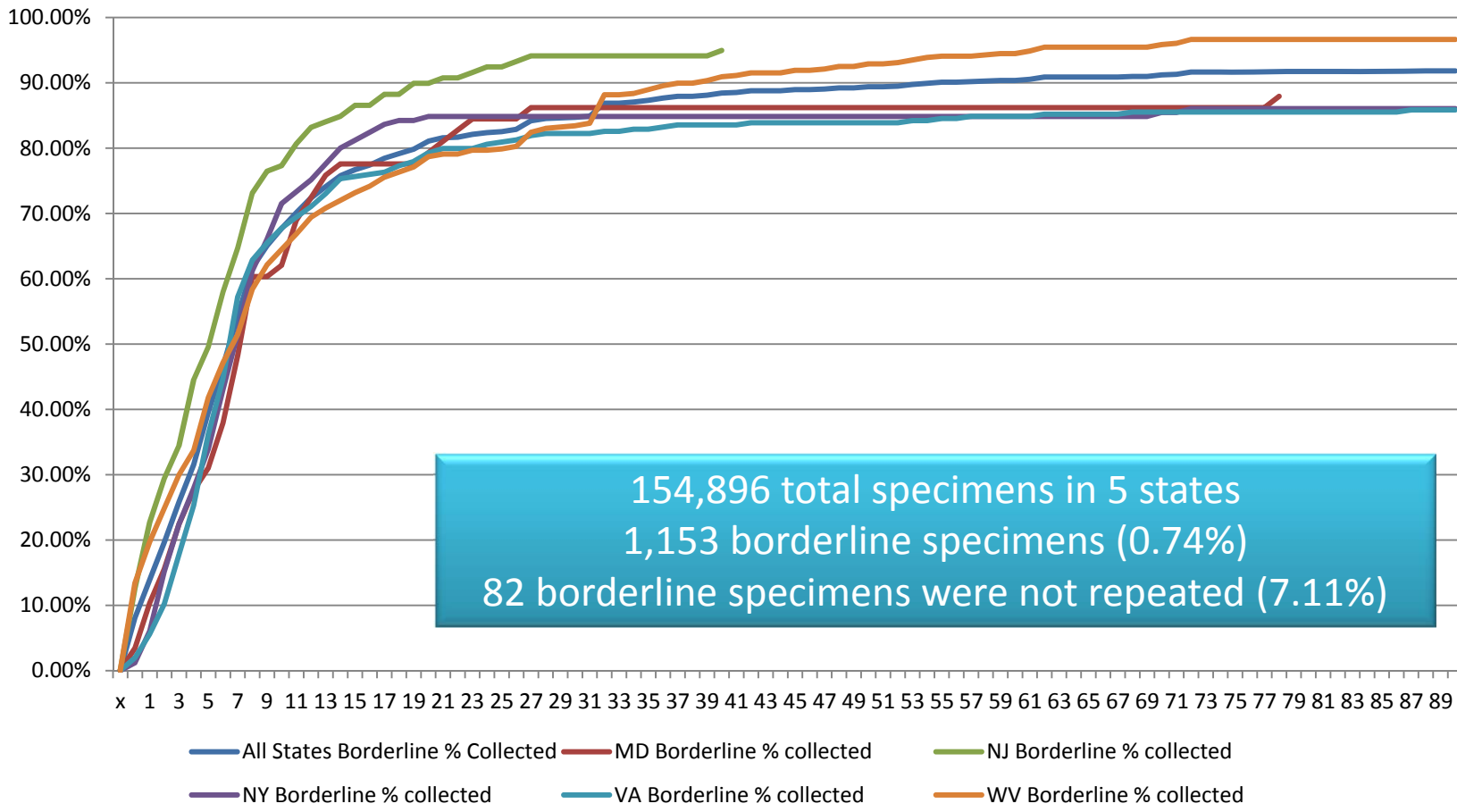
- 8% (range 1% - 13%) collected on the day of notification
- 54% (range 48% - 65%) collected within a week
- 76% (range 72% - 85%) collected within 2 weeks
- 85% (range 82% - 94%) collected within 30 days



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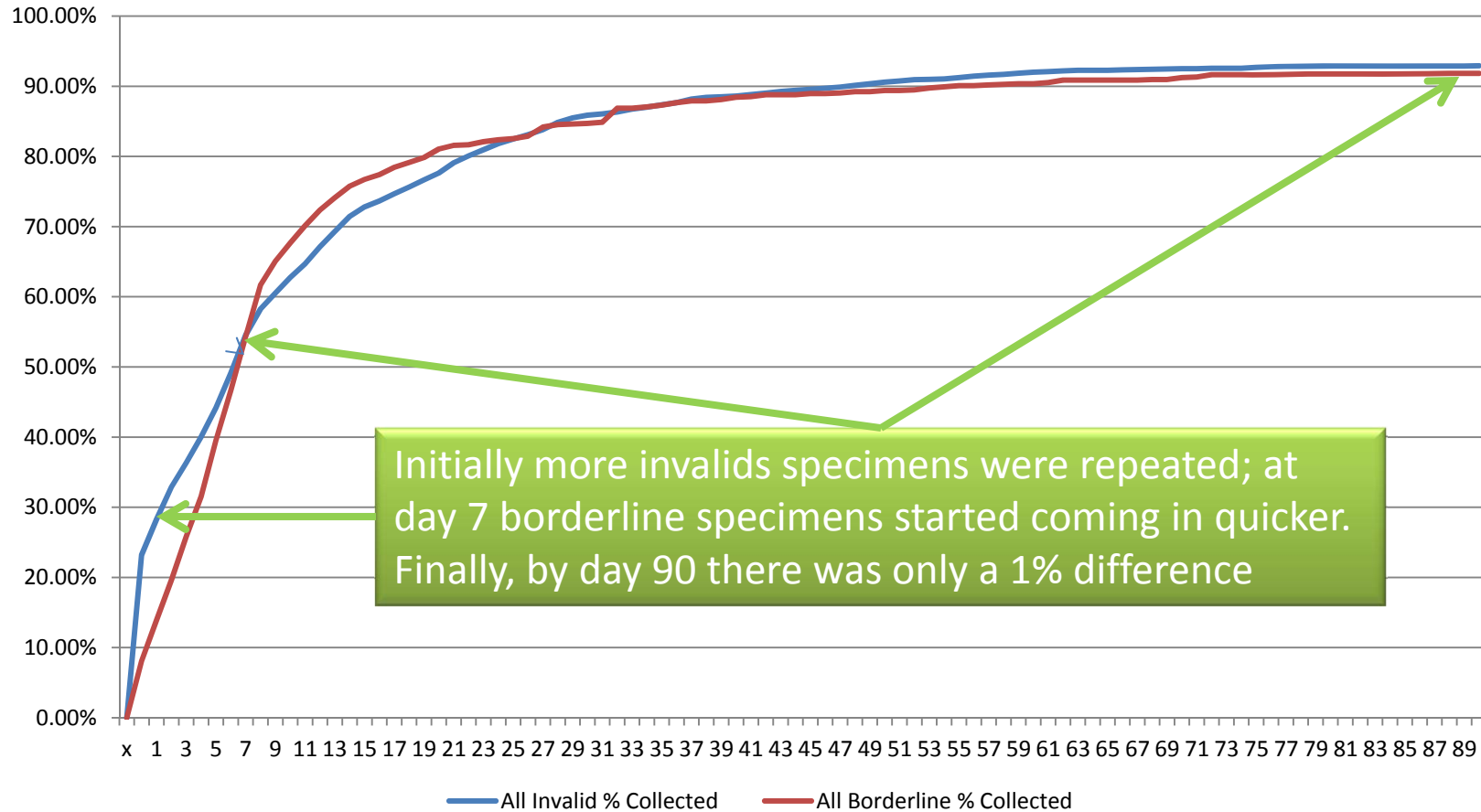
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## Borderline Data For All States and Combined



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## Comparison of % of Total Invalid Collected to % of Total Borderline Collected



Initially more invalids specimens were repeated; at day 7 borderline specimens started coming in quicker. Finally, by day 90 there was only a 1% difference



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## Discussion

- Except for the number of repeat specimens received on the day of notification (23% for invalid and 8% for borderline), PCP responses to invalid and borderline results are similar
  - PCPs may know ahead of time that a specimen was drawn too early or not well collected and anticipate the invalid result, but not the borderline result
- While the NBS programs request a repeat DBS in response to borderline results, some PCPs may choose to send a specimen to a private lab for confirmation
  - The NBS program may not receive those results promptly
- This study did not ask if the PCP was correctly identified on the DBS form
  - Finding the correct PCP could cause delays
- This study did not ask if the family was unavailable for follow-up



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# Next Steps

- Even though the results of this study showed that PCPs are generally responsive to invalid or borderline results, the NBS FU Interest Group plans to develop an educational campaign to remind the PCPs of the importance of prompt response to all NBS results:
  - If a specimen is invalid, a newborn has not yet been screened
  - Newborns with borderline results, while generally determined to be unaffected, are until proven otherwise, at increased risk for one of the conditions on the NBS panel – in NYS approximately 1:300 newborns are diagnosed with one of the conditions on the panel (excluding HIV and hemoglobinopathy trait)



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# Questions and Discussion

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