

Newborn Screening Quality Improvement Project

Reducing Turn-Around Time to Confirm Babies with Hemoglobinopathies in Nebraska

2013 Joint Meeting of the Newborn Screening and Genetic Testing Symposium,
and
International Society for Neonatal Screening

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Atlanta, GA
May 5-10, 2013

Hemoglobinopathy Turn Around Time

(Result notification to confirmatory specimen collection)

- ▶ Follow-up Specialist communication of perceived excess turn around time & effort
- ▶ Data analysis of TAT for all conditions and types supports the perception

Result/condition	Mean	Median	Range
Bio	2.8	1.0	-4.25 to 14
CAH	4	1	0 to 20
CPH	1.67	1.0	-3 to 14
CF (rec sweat @ 2wks)	7.33	7	5-9
Gal	5	5	5
Hgb Clinically Significant	4.5	5	0 to 9
Hgb Clinical Significance Unknown	11.52	4	0-119 days with 1 not confirmed
Hgb Likely trait	12.2	7	0-181 days with 9 not confirmed
MS/MS Significant	2	2	-1 to 5
MS/MS slight/abn	2.26	1	0 to 13
MS/MS hyperal	N/A	N/A	N/A
Unsatisfactory	7.44	5	1 to 45

2012 1st & 2nd quarter
 Time from result notification to
 confirmatory specimen collection

Why the difference?



Look at NBS Registry Data

- 187 mothers, ages 15–43 (mean and median 26)



Mom's survey

- 32 responses (17% response after adjusting for undeliverable/no address)

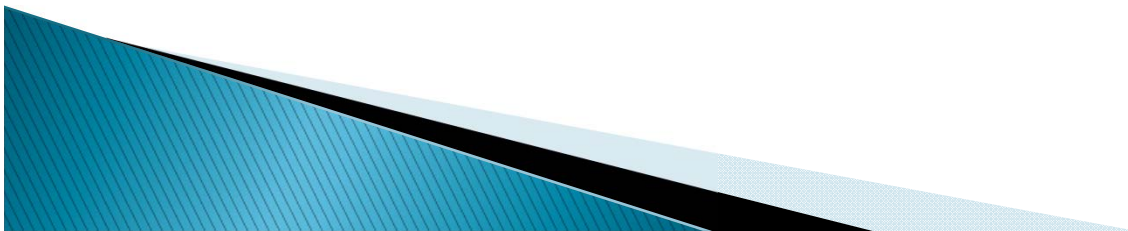


Baby's Health Care Providers

- 22 of 129 (17% response)

Registry

- ▶ Registry includes:
 - baby and mother demographics
 - physician info
 - documentation of follow-up activities (e.g. when notified, 2nd requests etc.) and
 - dates / ages at confirmation, diagnosis and initiation of treatment or intervention



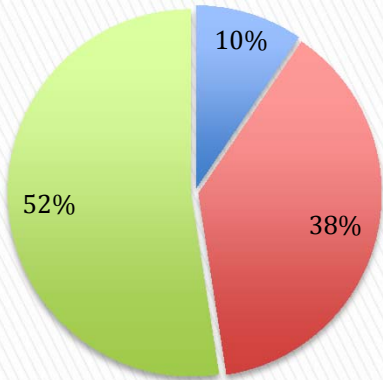
Mother's survey

- ▶ How they were told (phone, clinic visit, both)
 - ▶ How soon they took baby back in
 - ▶ Content communicated by their baby's health care provider
 - ▶ "Worry" factor
 - ▶ Problems/barriers
 - ▶ Facilitating factors
 - ▶ Age & Education
- ▶ Limitations:
 - Retrospective
 - Responses NOT matched to registry data so could not verify T-A-T accuracy
 - Did not ask what type of hemoglobinopathy their infant's result showed, so could not stratify "urgency".

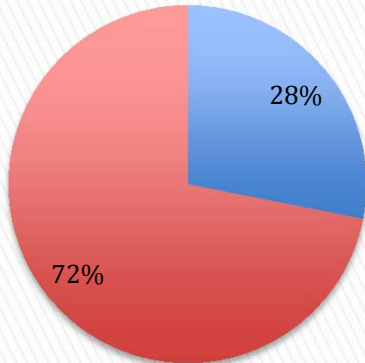


Mothers demographics Registry vs. self report

Mother's Age

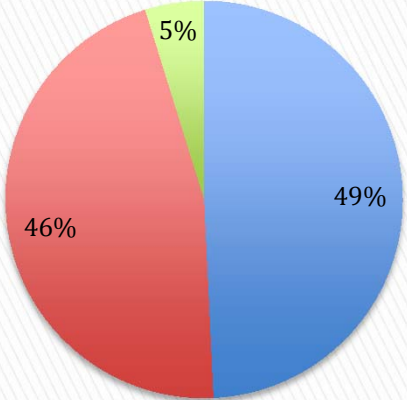


- Less than 20 (N=18)
- 20-25 (N=71)
- Over 25 (N=98)

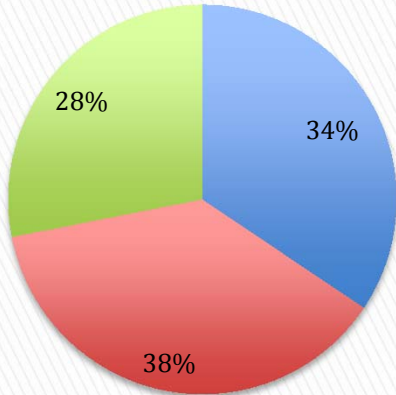


- 20-25 (N=9)
- Over 25 (N=23)

Mother's education



- High school or less (N=92)
- Bachelors or some college (N=86)
- Masters or Phd (N=9)

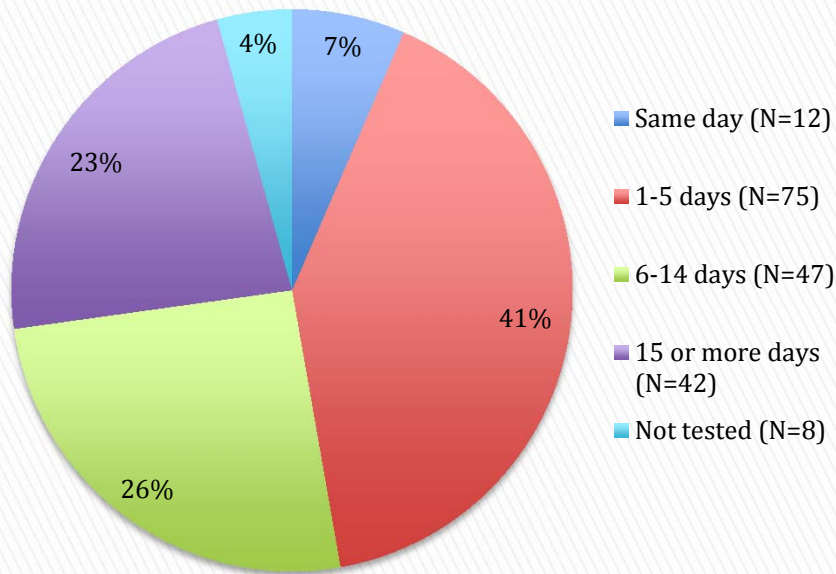


- High school or less (N=11)
- Bachelors or some college (N=12)
- Masters or Phd (N=9)

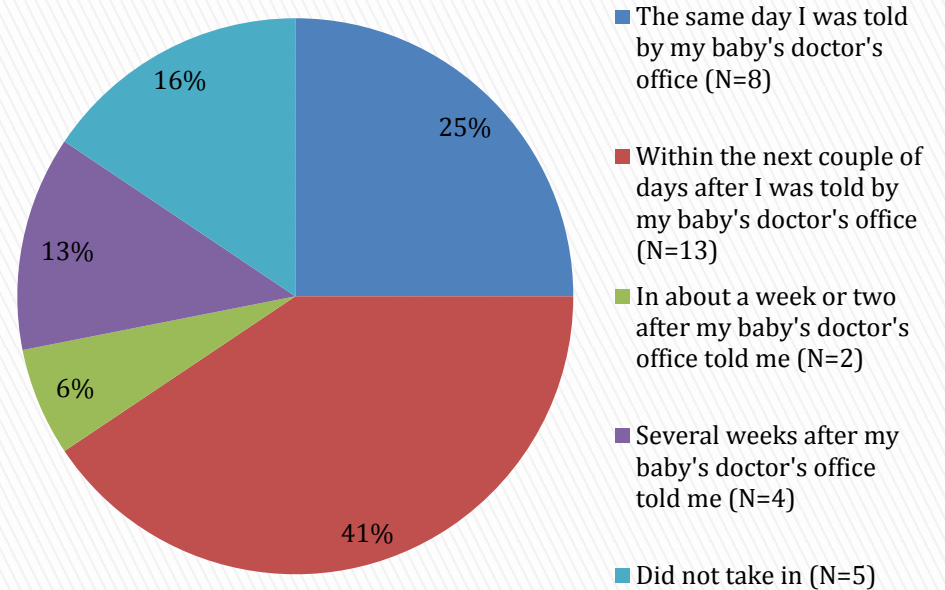
Registry

Mother's self report

When Baby was taken in for confirmatory test (Registry vs. Self Report)



Registry



Mom's self-report

Associations considered:

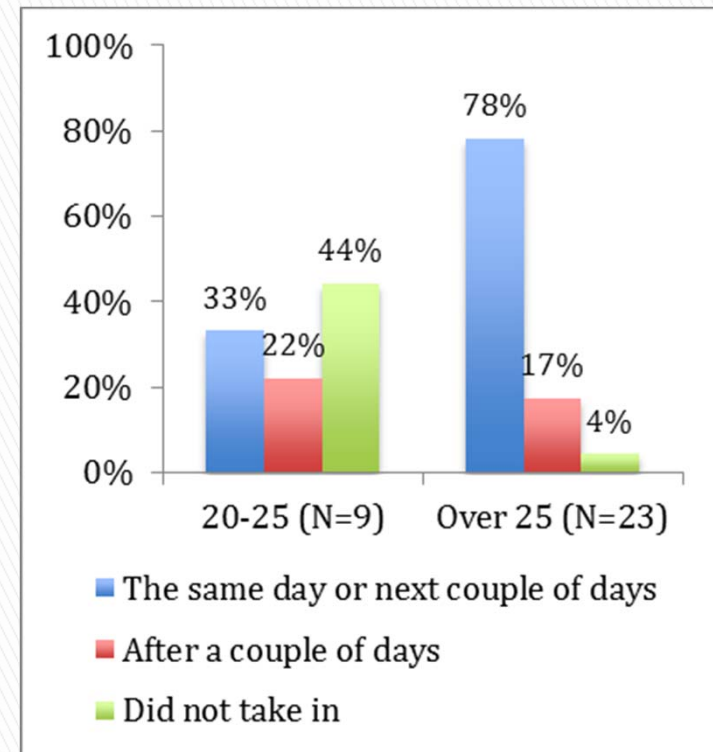
- ▶ Relationship between turn around times and:
 - mother's age
 - education
 - mode of health care providers' communication of abnormal result
 - level of healthcare provider's concern as perceived by mother
 - whether health care provider gave mothers reason to be concerned, or reason to NOT be concerned
 - whether health care provider explained what the results meant for the baby, or for future babies, and
 - whether health care provider encouraged mom's to take baby in within next few days or not



Factors with positive influence for faster turn around

- ▶ Older mothers were significantly more likely to self report having their baby tested within a couple of days

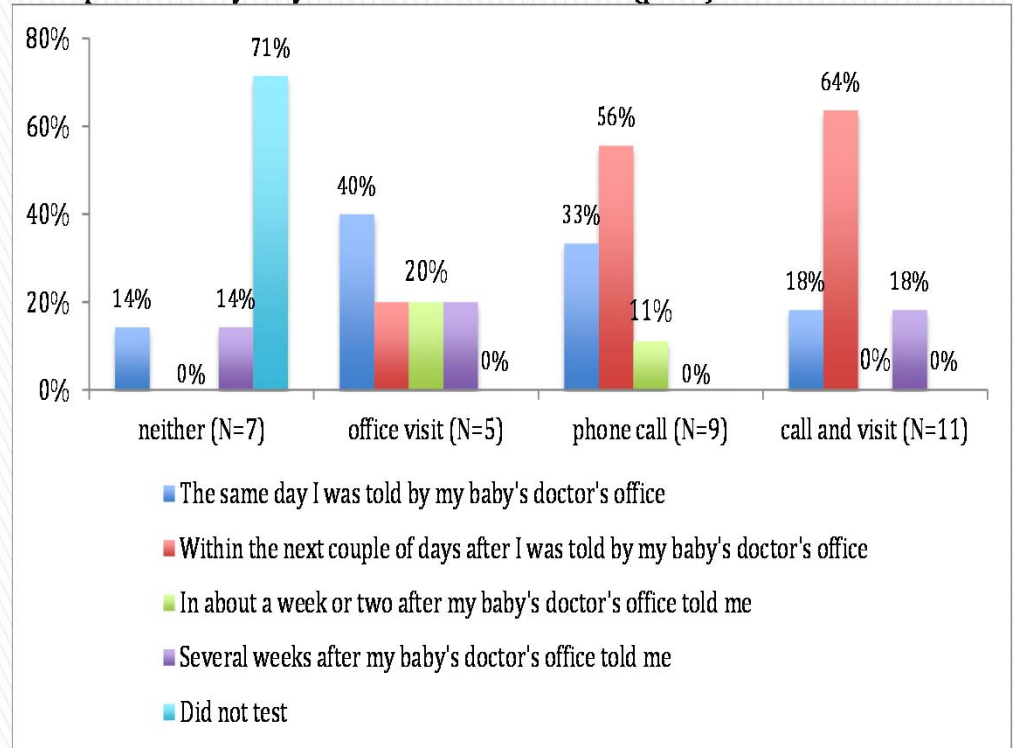
Mother's Survey: TAT by mother's age ($p < .5$)



Factors with positive influence for faster turn around

- ▶ Overall, mother's notified by phone were the most likely to have their baby tested within a couple of days.
- ▶ They were also more likely to be told "why" the test was needed when notified over the phone

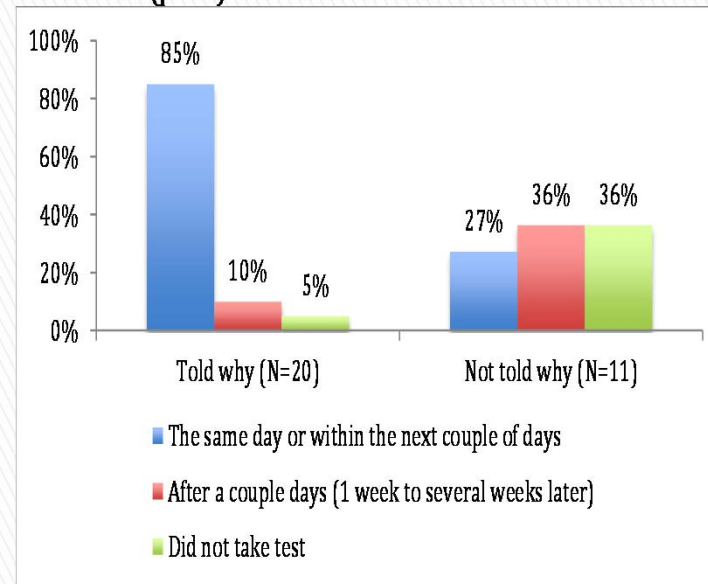
Self-reported TAT by baby's doctor's office notification. ($p < .01$)



Factors with positive influence for faster turn around

- ▶ Babies were more likely to be tested early if the doctor's office told the mothers "why" they needed to do so.
- ▶ ...and if they were told what the screen result might mean for their baby's health

Self-reported TAT by baby's doctor's office telling mothers why testing was needed. ($p < .01$)

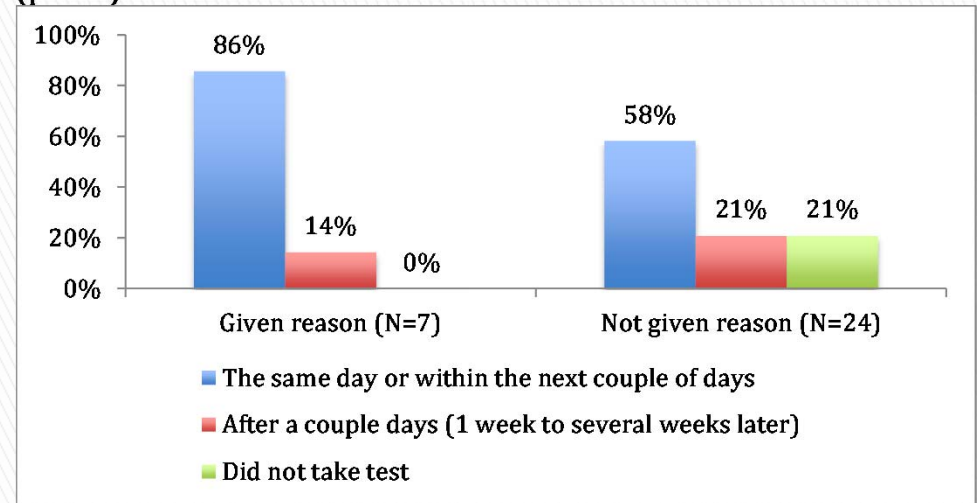


Other findings:

- ▶ Sense of worry:
 - Although reported “worry” was greater if notified of results *only* at clinic visit (vs. phone or both), sense of worry was NOT associated with mothers educational level, age, or faster or slower turn around times.
 - A double notification (e.g. phone *and* clinic visit) was however associated with reduced worry.



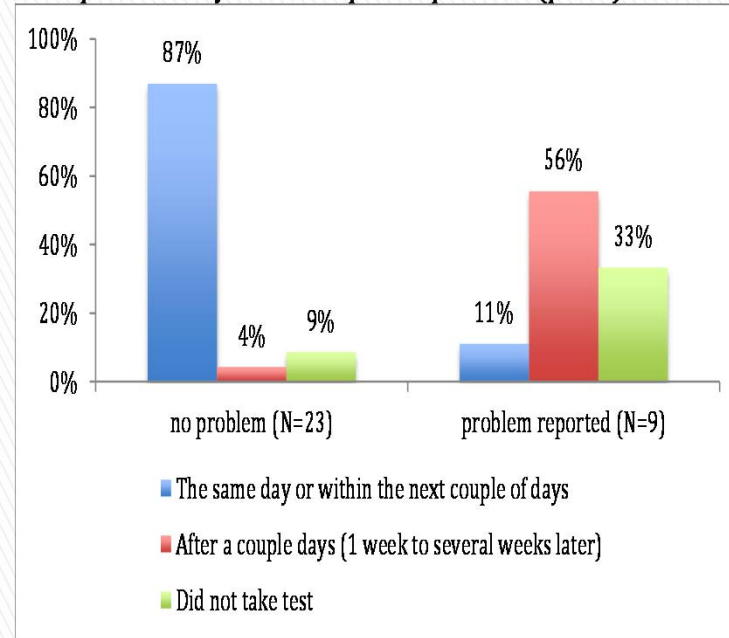
Self-reported TAT by baby's doctor's office providing reason(s) to worry. (p=n.s.)



Factors with positive influence on faster turn around

- ▶ Mothers who reported no problems such as lack of insurance or transportation were far more likely to get confirmation within a couple of days

Self-reported TAT by mother's reports of problems. ($p < 001$)



Developed insert card for parents to take with them to baby's healthcare provider appointment

Baby's Newborn Screen

Some parents bring a **list of questions** to ask their baby's doctor. Here are some questions you might want to ask.

- ◆ What were the results of my baby's newborn screen?
- ◆ What do these results mean for my baby's health?
- ◆ What needs to happen next?
- ◆ How will this affect my baby when he/she grows up?
- ◆ Is there any treatment needed for this condition?
- ◆ If my baby does have this condition, how did he/she get it?
- ◆ Should anyone else in the family be tested?
- ◆ Could I have another baby that has this condition or something else?
- ◆ Can this condition turn into anything else?

Resources for Parents

You might want to consider genetic counseling to discuss testing options and family risks. If you wish to schedule an appointment call (402) 559-6418 or (800) 656-3937.

Some of the specialists in blood diseases are at the Nebraska Medical Center (402) 559-7257 and also at Omaha Children's Hospital (402) 955-3950.

You can also visit the following websites:

For the Nebraska Newborn Screening Program: www.dhhs.ne.gov/nsp/

For information about newborn screening: www.babysfirsttest.org

If you have questions about newborn screening you can call the Nebraska Newborn Screening Program at (402) 471-0374.

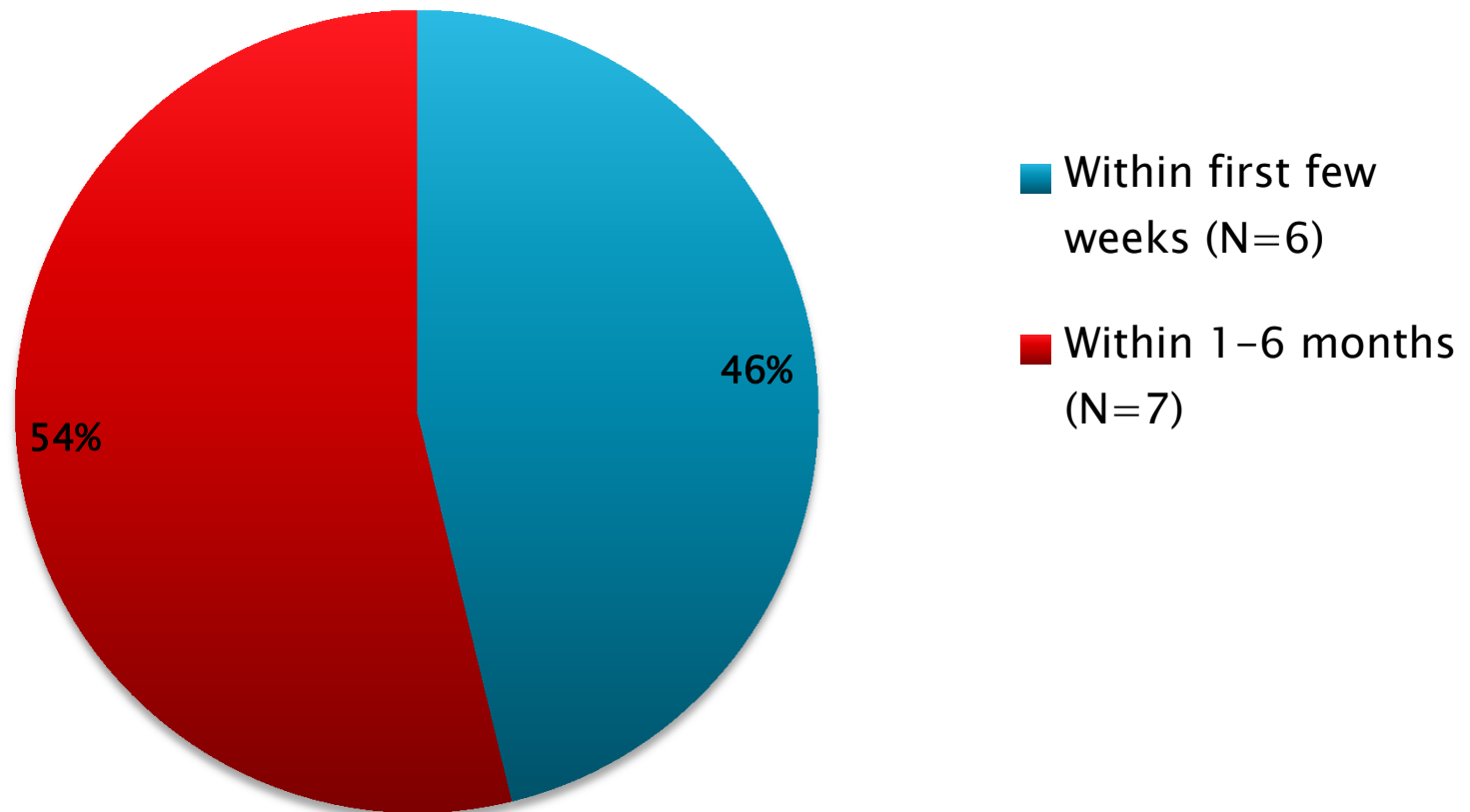
Health Care Provider's survey

- ▶ Beliefs about necessity, importance and timing of confirmatory testing
- ▶ Perceptions about what barriers mothers face
- ▶ Which of several suggested procedures their office follows to ensure follow up
- ▶ Willingness to adopt “scripts” using principles of risk communication

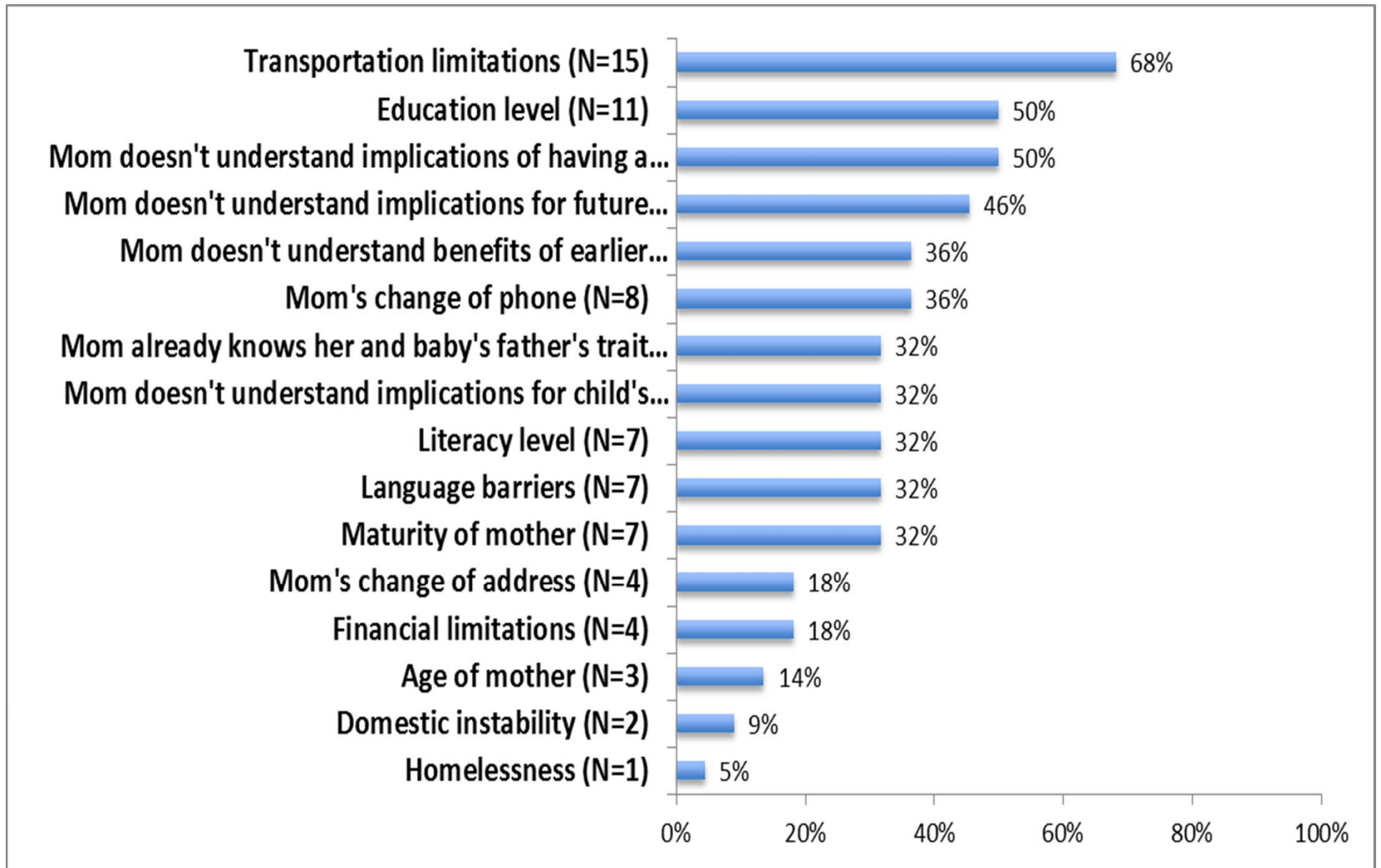


Physician survey results

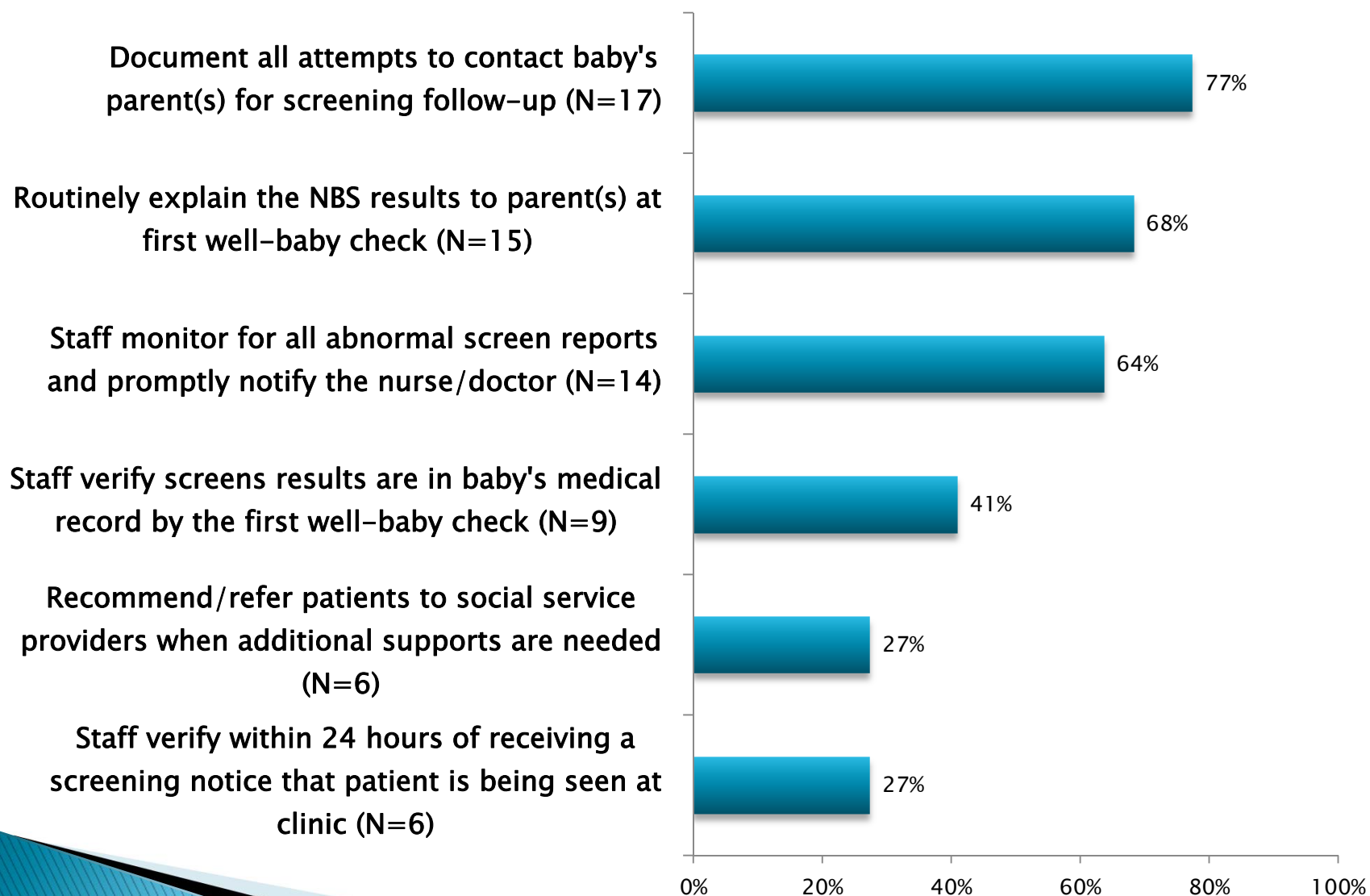
Proportion of physicians who feel confirmatory testing should be done within a specific timeframe.



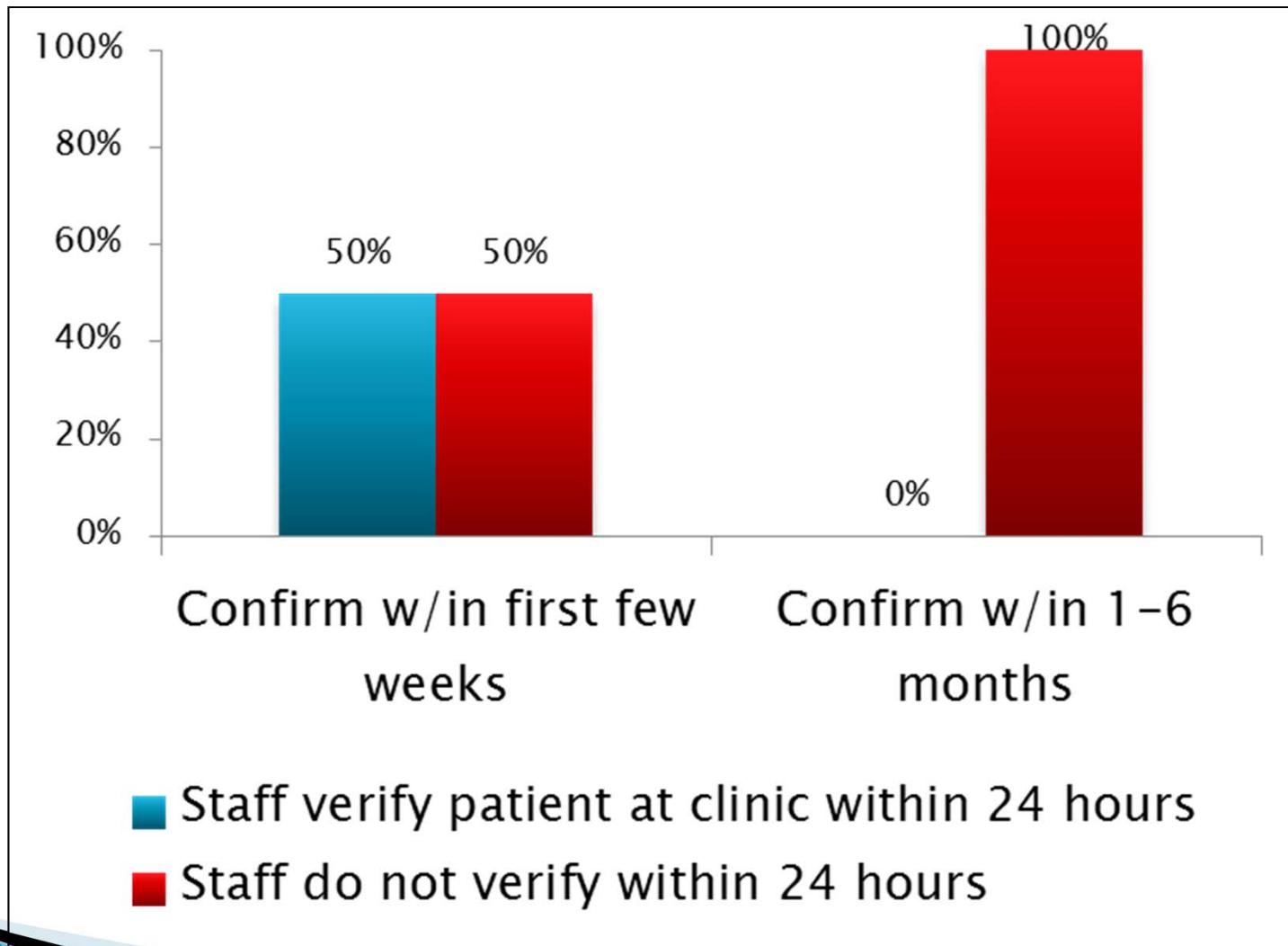
Physician Perceptions of Barriers That Contribute to Slower Response Times for Testing



Proportion of physicians reporting procedures practiced at their clinic.



Health care provider beliefs correlate to office practices that support their beliefs.



So what to do?

▶ Factors to impact:

- Communication practices of health care provider offices
- Beliefs of health care providers
- Understanding of health care providers of importance and value of rapid follow-up

▶ Actions:

- Ped hem developed YouTube videos with CME's for confirming FS, FAS, FA+Barts, FAV (link added to ACT sheets)
- Mother notification letters (from program) revised
- Physician letters (from program) revised
- Physician ACT sheets revised

Developed and distributed “Sooner is Better” brochure to educate health care providers



Newborn Screening Hemoglobinopathy Follow-up Information for Health Care Providers

The Newborn Screening Program has analyzed the time from notification of an abnormal screen result to the time the baby's repeat or confirmatory specimen is collected for all of the screening tests. It was found that the time was longer for the hemoglobinopathies than for any other condition.

The outer time limit for when babies with sickle cell disease or other clinically significant hemoglobinopathies should be treated is 2



months. This means that the confirmation has been done, the patient has seen a hematolo-

gist and parental education has begun. This also correlates with the approximate time by which prophylactic penicillin must be started because protective maternal antibodies have decreased.

For all hemoglobinopathies, sooner is better when delivering comprehensive care. Caregiver education needs to occur earlier for the best outcomes.



For all babies with abnormal hemoglobinopathy results **“sooner is better”** for confirmation.

Here are some of the reasons why:

- ◆ Our society has become much more mobile. A patient that is expected to follow up in your office may move and/or change phone numbers. Reaching out and having the confirmation done prior to these changes **reduces the effort required** to contact the family.
- ◆ Confirming baby's trait status is important in order to **document it in their medical record**. While with most traits no health effects are usually expected in children, knowledge of this status can be critical later. For those with sickle cell trait, in conditions of low oxygen and heavy exertion, some patients may be at risk of deep vein thrombosis and rhabdomyolysis. Other traits are known to interfere with some methods of Hemoglobin A1C measurement.
- ◆ A confirmed trait may have **implications for the entire family**. Parental studies may be needed. Moms have become pregnant again in a short time frame. Delaying the confirmation of a trait may delay mom's learning about her reproductive risk prior to another pregnancy.

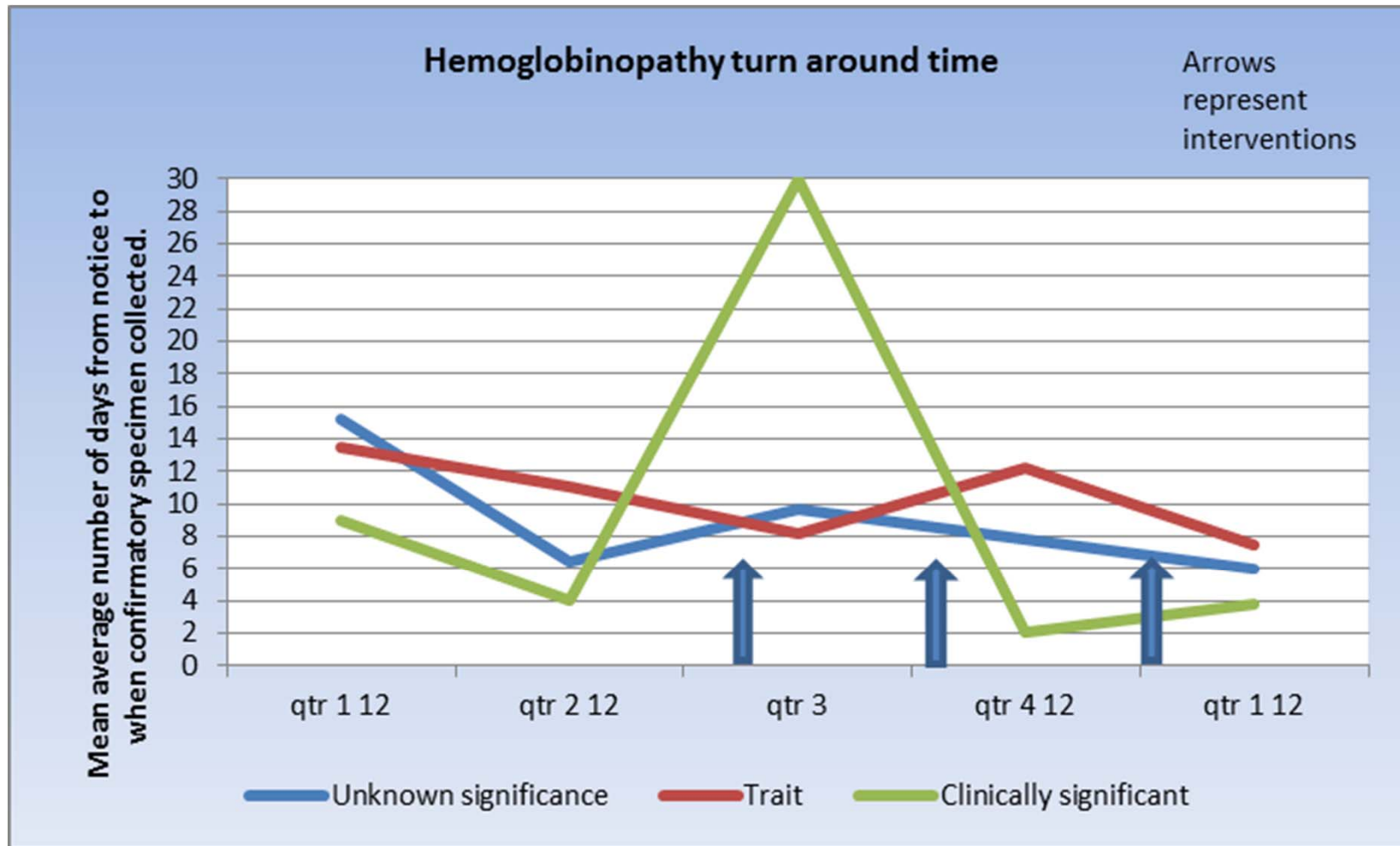
If the family decides to share the information, relatives who are in the reproductive age group may benefit from knowing about the trait.

- ◆ Because fetal hemoglobin production decreases with age, **the opportunity to confirm the presence of Bart's hemoglobin may be lost** with a delay in confirmation. Much more expensive DNA analysis would be needed to confirm alpha thalassemia status without confirmation of the presence of Bart's hemoglobin.
- ◆ Without rapid contact the opportunity for confirmation of trait status may be lost. A family may change physicians without notifying your office. Therefore the complete medical record may not be obtained by the new physician and the **possible “trait” status may not be confirmed**.

Remember: When receiving an abnormal hemoglobinopathy result that “sooner is better” for reaching out to the family and having the confirmatory testing completed.

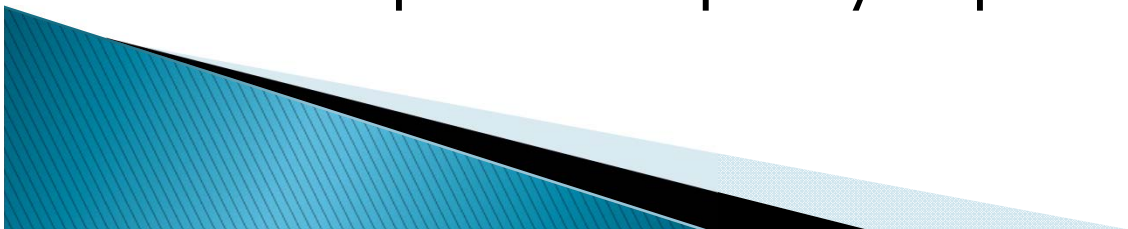
Nebraska State Law requires the attending physician to follow-up on abnormal screens.

Progress report data:



Acknowledgement:

- ▶ The initial data analysis of registry data, mother survey results, and healthcare provider survey results was completed by Mindy Anderson-Knott and was supported by: the Cooperative Agreement Number 5U58CD001310-03 from The Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.
- ▶ A special thanks to Colleen Svoboda and Jeff Armitage of the Nebraska Department of Health and Human Services for supporting this collaboration, and for making the opportunity available for further staff development in quality improvement.



Acknowledgement

- ▶ Special thanks to contributors to this project:
 - Mindy Anderson–Knott, Data Analyst
 - Krystal Baumert, NBS Follow–up Coordinator
 - Karen Evans, NBS Follow–up Specialist
 - Charlene Gondring, Office of Public Health
 - James L. Harper, MD Pediatric Hematologist
 - Mike Rooney, NBS Administrative Assistant
 - Mother’s of babies with hemoglobinopathies who responded to the survey
 - Health care providers serving babies with hemoglobinopathies who responded to the survey

