



**Midwest Genetics  
Network**  
Region 4

# Return of Newborn Screening Results

A Project of the Midwest Genetics Network Provider Education  
Workgroup

Presented to the Advisory Committee on Heritable Disorders in  
Newborns and Children - November 1, 2018

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# What do families want regarding NBS results?

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- Typical focus on POSITIVE results
- Well established process for abnormal/positive results
- 95+% of results are NORMAL

## *What about those?!*

- Quality assurance project to learn from families about NBS results return
- Survey of families in MN re receipt of results

# Why normal result reporting matters

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*“I do not remember ever receiving Leo’s results about the newborn screen until after his stroke. I remember being told **no news is good news** by someone from the hospital.”*

– Leo’s mom



Despite a **normal newborn blood spot screen**, Leo was diagnosed with cobalamin A methylmalonic acidemia at 16 months of age following a stroke and permanent brain damage

# A quality improvement project initiated to assess:

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- If families received and understood their normal screening results
- How negative newborn blood spot results are handled at several clinics in MN
- Where improvements are needed for the efficient and effective communication of negative results to providers and families



# Do parents in MN receive negative results?

- Survey sent to parents **4 weeks** after birth
- Chosen based on:
  - Negative blood spot screen results
  - Specified provider/clinic at time of birth
- **1648** surveys sent
  - **257** surveys received
  - Response rate: **15.6%**

## Newborn Screening Results Parent Survey

DEPARTMENT OF HEALTH  
NEWBORN SCREENING

in partnership with the University of Minnesota

Purpose and Instructions:  
We are looking to review and improve how parents learn about their child's newborn screening results. Your input will help shape future practices throughout Minnesota. Please complete the questions below to share your experience!

Take the survey online!  
[goo.gl/kUviTw](http://goo.gl/kUviTw)

1. Are you familiar with the newborn blood spot screen (sometimes called the Guthrie test, PKU test, or heel prick test)?

Yes       No       Don't Know

2. Did you receive your child's newborn blood spot screening results?

Yes       No       Don't Know

If you answered "Yes" to question 2, please complete this question:

2a. How did you receive your child's newborn screening results (check all that apply)?

In-Person from Pediatrician/Provider       Over the phone from Clinic Staff  
 Letter in the mail       MyChart message  
 Other \_\_\_\_\_

3. Do you feel like you understand the difference between a screening test (like the newborn screen) and a diagnostic test?

Yes       No       Don't Know

4. What is the name of your child's primary care clinic?

Fairview Children's Clinic       Partners in Pediatrics       West Side Community Health  
 Mayo Clinic       Southdale Pediatrics       Other \_\_\_\_\_

5. What do you think is the best way to learn about your child's newborn screening results and what they mean?

MyChart       Paper Brochure       Online Video       Email  
 Text       At Clinic Visit       Phone Call

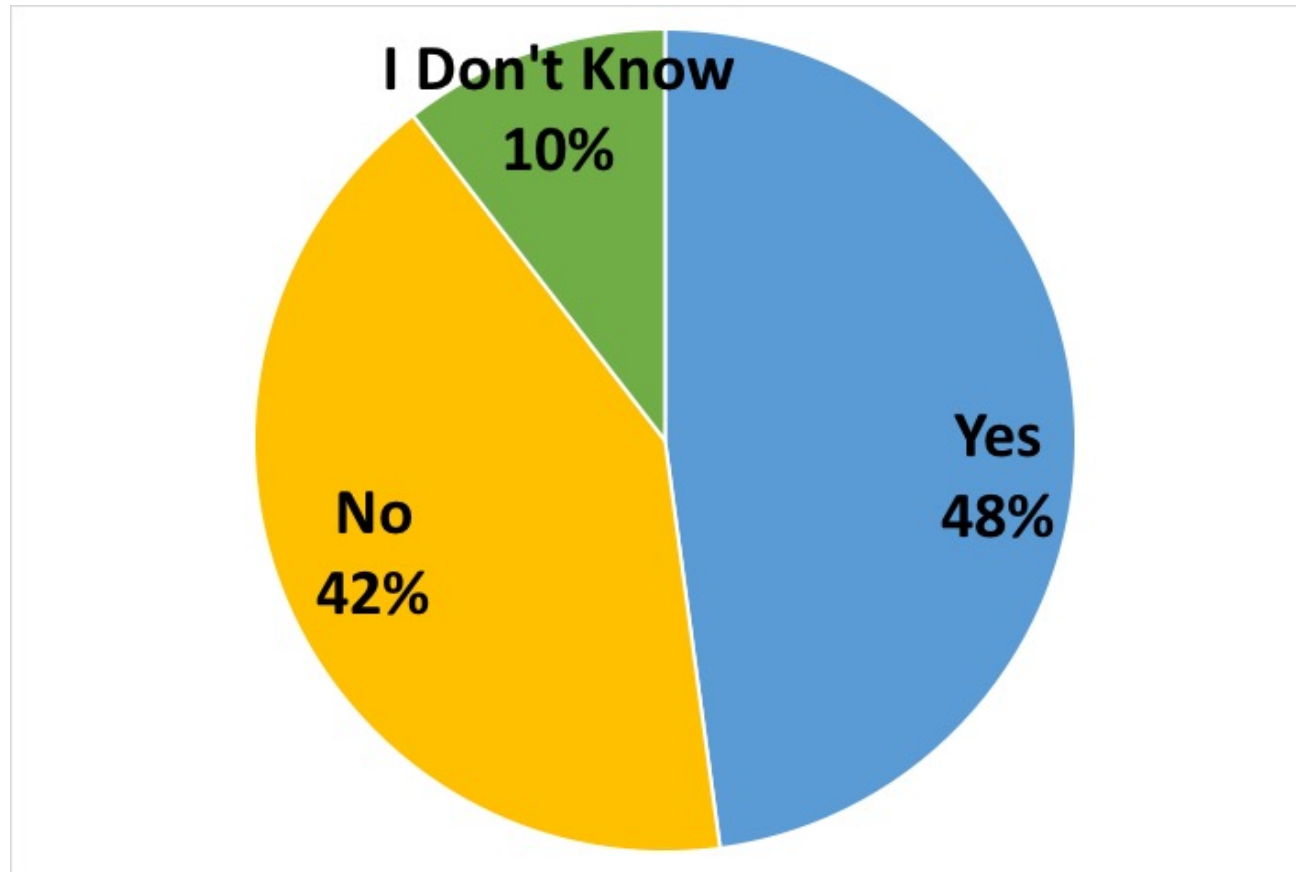
6. Were you satisfied with your experience getting your child's newborn screening results? How could it be improved?

\_\_\_\_\_

\_\_\_\_\_

Have questions about this survey? Contact Whitney Thompson at [thom2711@umn.edu](mailto:thom2711@umn.edu)  
Have questions about Newborn Screening? Contact Amy Gaviglio, MS, CGC at [amy.gaviglio@state.mn.us](mailto:amy.gaviglio@state.mn.us)

# Percent of Newborn Blood Spot Results Received



n=257

# MGN Provider Education Workgroup

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Effort to give education to providers re return of NBS results

- Vehicle: MOC4 quality improvement activity
- Planned activity: assess return of NBS results
- Training activity: Three modules regarding NBS and return of results
  - Session 1: What is newborn screening
  - Session 2: Return of NORMAL screening results
  - Session 3: Return of Borderline or Positive results

# What is MOC4?

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## Four parts of Maintenance of Certification

- Professional standing (Licensure)
- Lifelong learning (CME)
- Cognitive expertise (Exam)
- Improving professional practice (Quality Improvement)

From the American Board of Pediatrics:

“You must participate in quality improvement (QI) activities to earn Part 4 credit. These can be small or large group, collaborative, web-based or other types. The ABP approves activities that are designed to assess and improve the quality of patient care and processes that will lead to improved child health.”

*(<https://www.abp.org/content/four-parts-moc>)*



# MOC4 offered through American Board of Pediatrics (in progress)

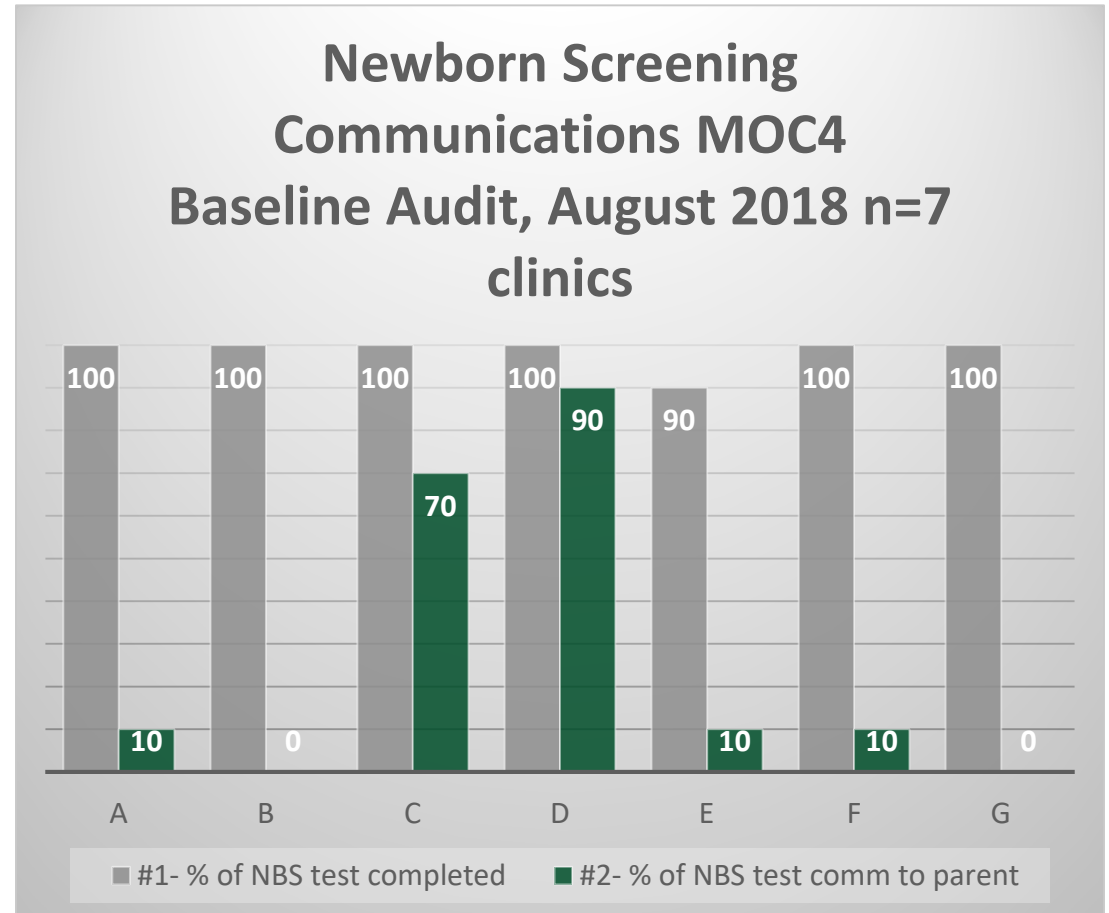
82 pediatricians enrolled

- Initial audit
- Virtual learning collaborative
- Follow up of intervention

Two learning sessions of  
three presented thus far

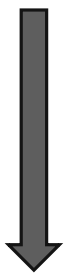
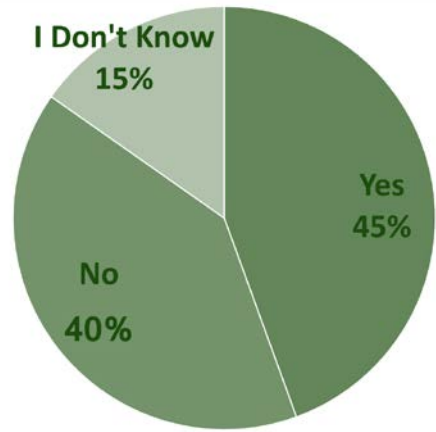
Initial audits taking place

- Data from 7 clinics

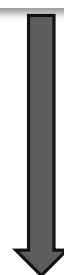


# Pilot: Normal blood spot results fact sheet at two clinics

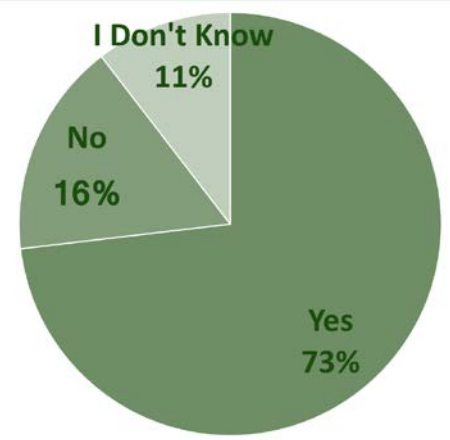
Percent of normal newborn blood spot results received by families



June – November 2017



Percent of normal newborn blood spot results received by families

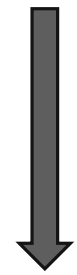


n=67

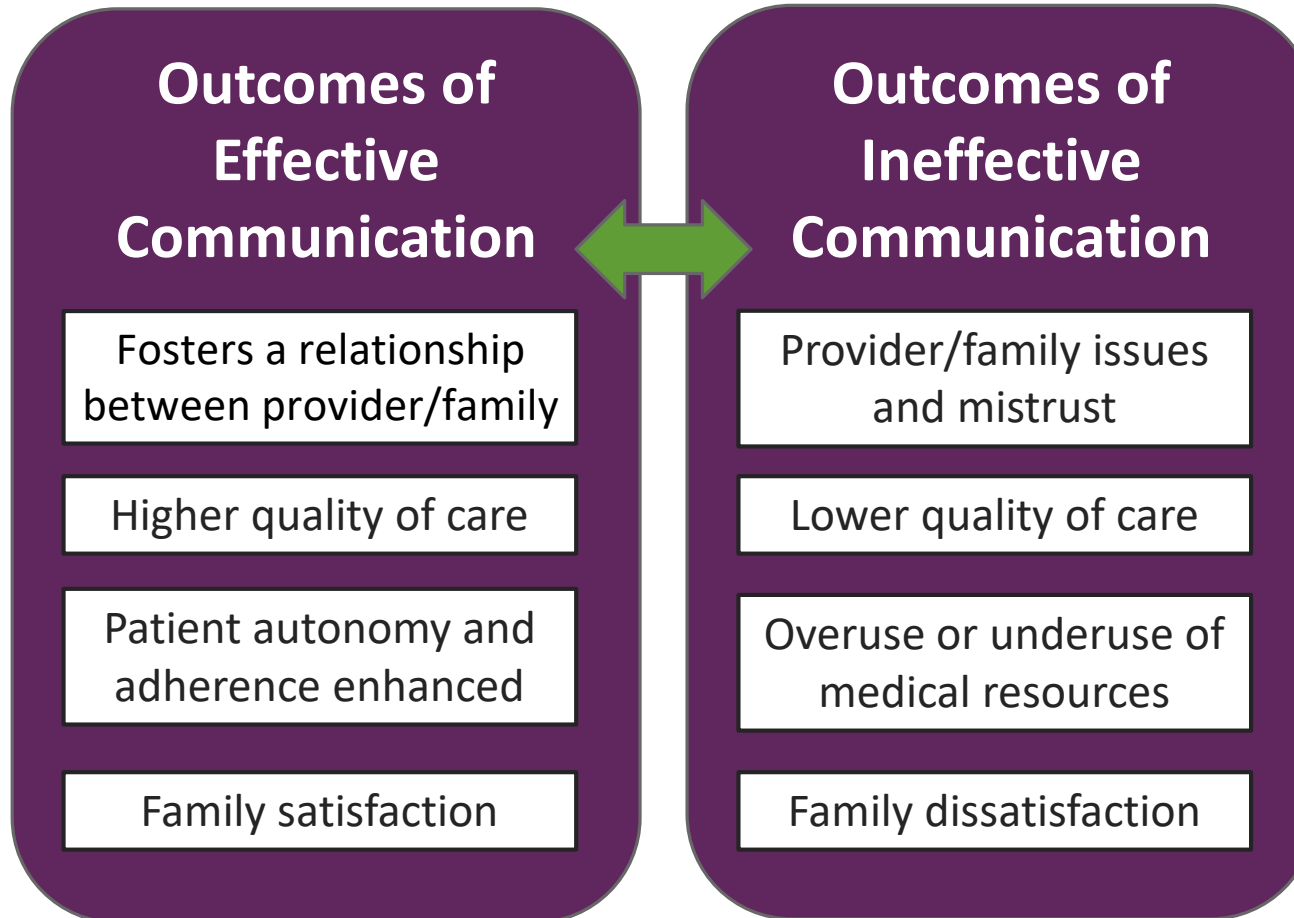
MOC4



April – September 2018



# Session 3: return of positive results





**THIS GUIDE WILL HELP YOU EFFECTIVELY COMMUNICATE [POSITIVE] NEWBORN SCREENING RESULTS TO PARENTS.**



Because this type of communication is not a routine activity for the primary care provider, the information below may be used to help frame the discussion with families to improve understanding of the screening result, adherence to follow-up recommendations, and the family's overall experience with newborn screening.

Families who have had [positive] newborn screening results have suggested that the following key points are important in helping families cope with the uncertainty of a [positive] newborn screening result and understand the next steps needed to gain certainty.

**S**hare the specific [positive] newborn screening result and associated condition(s) with the family.  
Help the family understand that a [positive] newborn screening result is serious, but that you are there to help guide them through the next steps.

**C**omprehension: Assess the family's understanding of newborn screening.  
Assess if the family recalls and understands the process of newborn screening.

**R**emind the family about the purpose of newborn screening and that it is not a diagnostic test, so it is important that timely follow-up confirmatory testing be done.

**E**ngage with the family and provide information at their desired level and pace.  
Offer to provide the family additional result-specific information provided by the state newborn screening program.  
Discuss information using non-medical terms, at the family's pace and desired level of detail.

**E**xplore the family's emotions.  
Explore with the family how they might use their support system or other support resources now and as they go through the diagnostic process.  
Remember there is a wide spectrum of how families may cope with this result (anxiety to denial). Tailor your discussion to help the family hear and retain the information discussed.

**N**ext steps: Discuss a shared plan and provide resources.  
Discuss with the family a shared plan that is concrete, specific, and includes the following:

- Where, when, and with whom is the next appointment?
- What testing will be considered and/or done?
- What should they watch for in their child while they wait?
- Who can they contact if they have additional questions or concerns?

Assess the family's understanding of the visit and information provided using teach-back methods, and provide valid websites for them to get more information.

# Next steps

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Complete initial MOC4 cycle

Engage additional providers in educational process

Assess improvements in initial participant's practice

Plan advanced practice engagement

Make educational materials available