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Region 4

Newborn Screening: Normal Results

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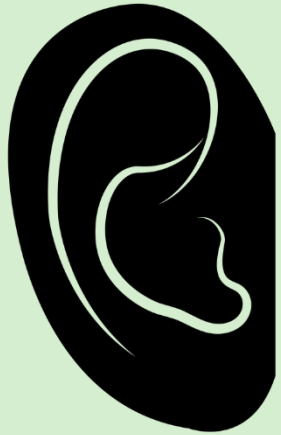
Learning Objectives

Objective 1: Define normal newborn screening (NBS) results and recognize their limitations

Objective 2: Understand current practices for providing normal NBS results to families

Objective 3: Identify where improvements are needed for the efficient and effective communication of normal NBS results to families



What is a normal newborn screen result?

Result meaning: The child is at low risk for having the condition(s)

Potential interferences/influences:

- Transfusion
- Specimen taken too early/late
- Feeding status

Key talking points when communicating results:

- Result indicates child is at low risk for having the condition(s) on the NBS panel
- No further action is needed at this time
- Screening is not diagnostic testing and NBS does not screen for all health conditions; still should remain clinically vigilant

*Over **95%** of US newborn blood spot results are **normal***

A quick note on terminology

States may use different terminology to refer to these results

- Normal
- Negative
- Within normal limits
- In-range

*For the remainder of this presentation, we'll use **"normal"***

What you may see in your own practice may be different, but we're talking about the same thing

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False normal results

"A 'negative' result means that the screen was normal for that particular disorder and no additional follow-up is required…

Note: Because newborn screening is not diagnostic testing, ***false negative*** *results may occur… Newborn screening should not replace diagnostic testing in any circumstance…"*

-Minnesota Department of Health

While false normal results are rare events, they are hard to track and can have serious health implications

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Why normal result reporting matters

*"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

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What's on the newborn screen, and who gets the results?

Hearing screen: Objective testing to determine hearing loss in the range where speech is heard. **Results are available for family before baby leaves the hospital.**

Pulse oximetry screen: Uses a painless sensor on the baby's skin to test for the presence of hypoxemia, which may indicate an undetected critical congenital heart disease. **Results are available for family before baby leaves the hospital.**

Blood spot screen: The baby's heel will be pricked to collect a small sample of blood. The newborn screening card is then sent to the state laboratory for analysis. It will include the contact information of the parents and the baby's primary care provider for the follow-up results. **Result reporting to family is a little more complicated…**

https://www.babysfirsttest.org/

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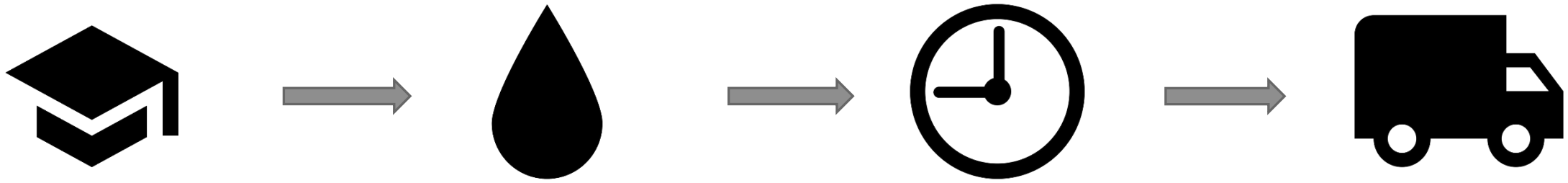
Blood Spot Process: Pre-Analytical

Families should be provided education about screening BEFORE the sample is collected, including the prenatal period.

Blood spot samples are recommended to be collected between 24 – 48 hours of age.

Specimens are dried horizontally for at least 3 hours prior to submission.

Specimens should be sent to the state screening program within 24 hours of collection.



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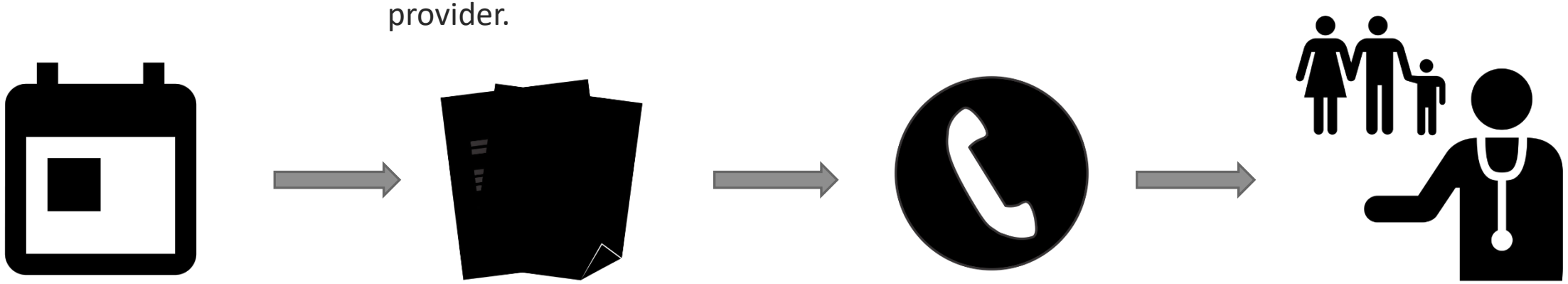
Blood Spot Process: Post-Analytical

Results should be available around 7 days after birth (positive results may be available sooner).

Normal results will be provided back to the submitting birth facility and should be forwarded to the primary care provider.

Positive results will be called out to the primary care provider and/or specialist.

Family should be notified by the primary care provider/specialist as soon as possible.



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What providers should communicate to families about normal newborn blood spot results

- Notification of normal result
- Disorders on state's screening panel
- Limitations of the screening test
  - *A normal result does not preclude the possibility of future disease*
- What symptoms to be on the lookout for despite a normal result

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Documenting and billing for discussion of normal NBS results

2022 ICD-10-CM Diagnosis Code Z13.228

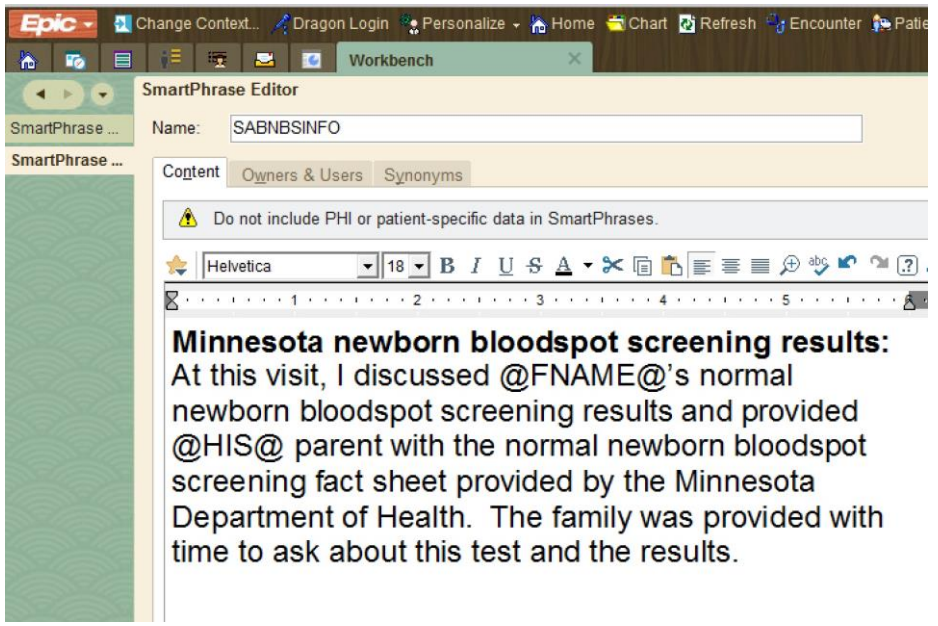
- **Encounter for screening for other metabolic disorders**

Synonyms

- Screening for endocrine, nutritional, metabolic and immunity disorders (done)
- Screening for metabolic disorder (done)

Present On Admission

- Z13.228 is considered exempt from POA reporting.



Adding this diagnosis code

- *Improves reimbursement*
- *Documents giving result for future reference in chart*

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A quality improvement project was initiated to assess:

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

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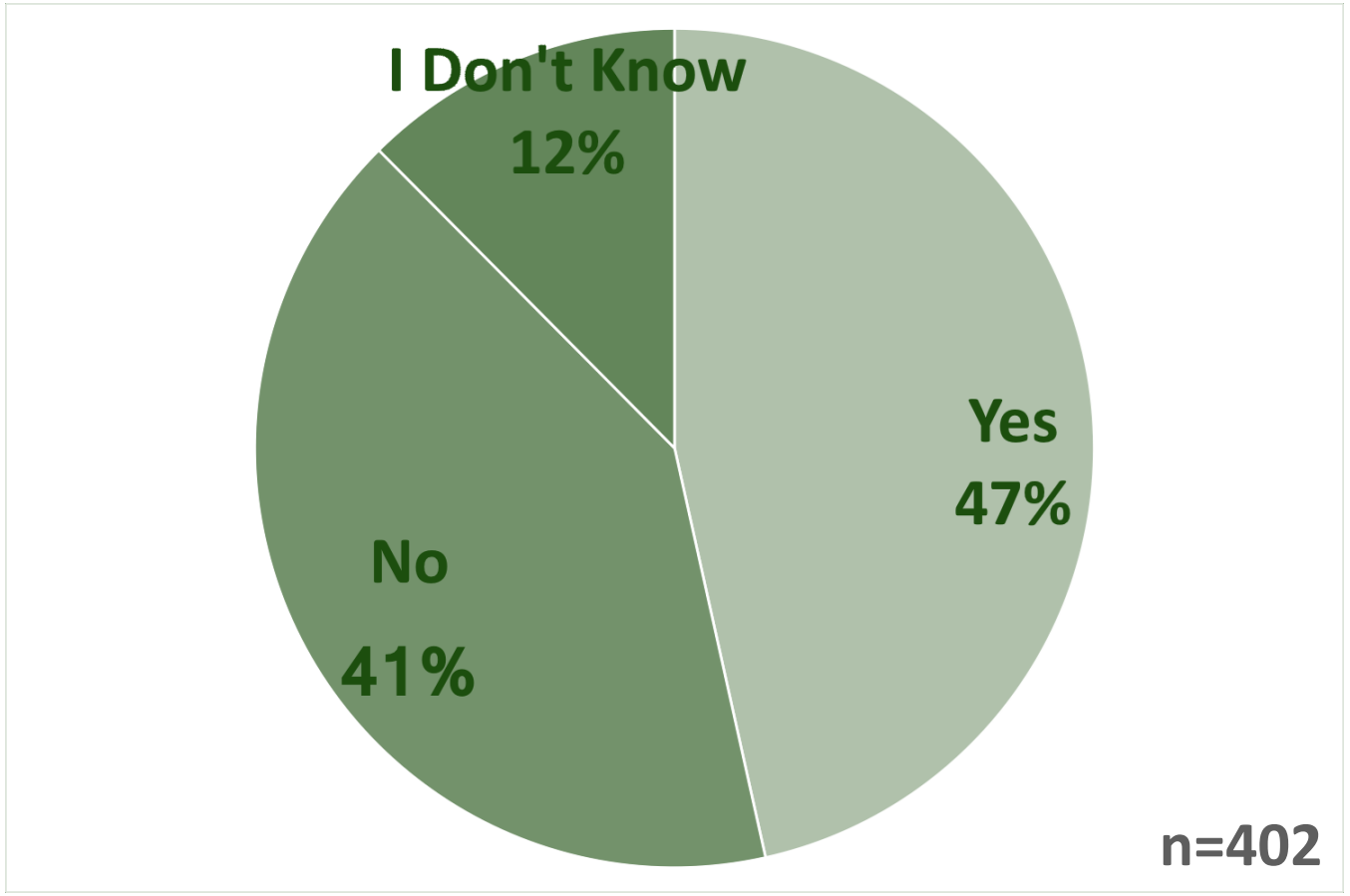
Percent of normal newborn blood spot results received by families



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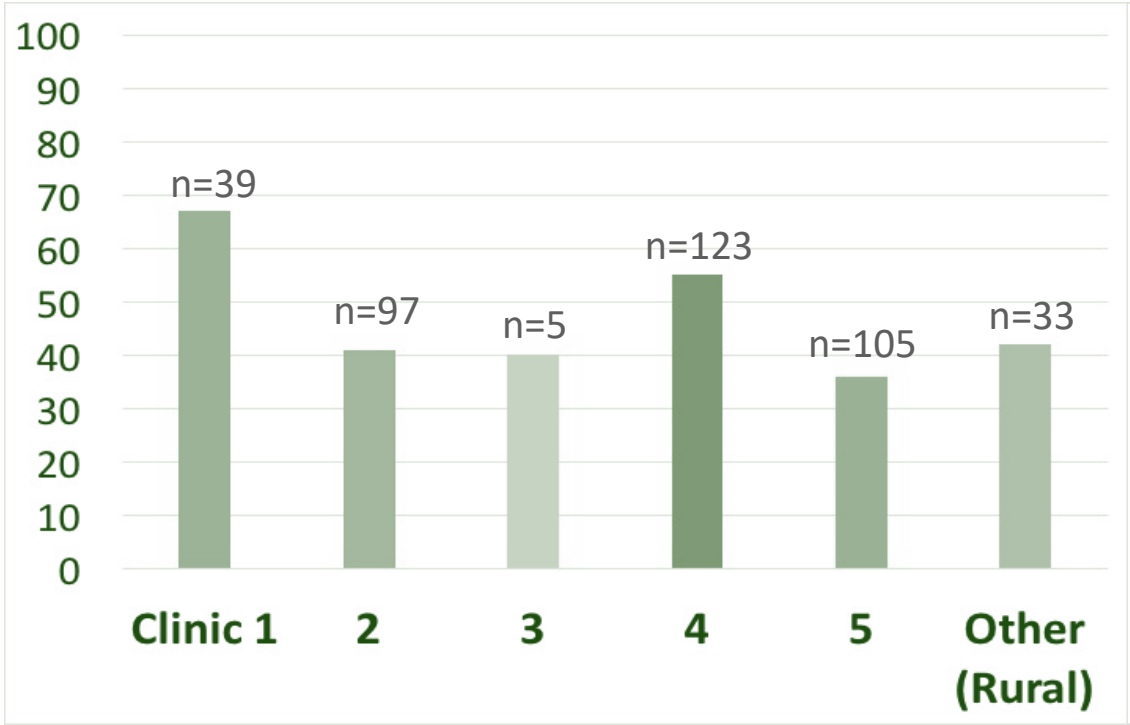
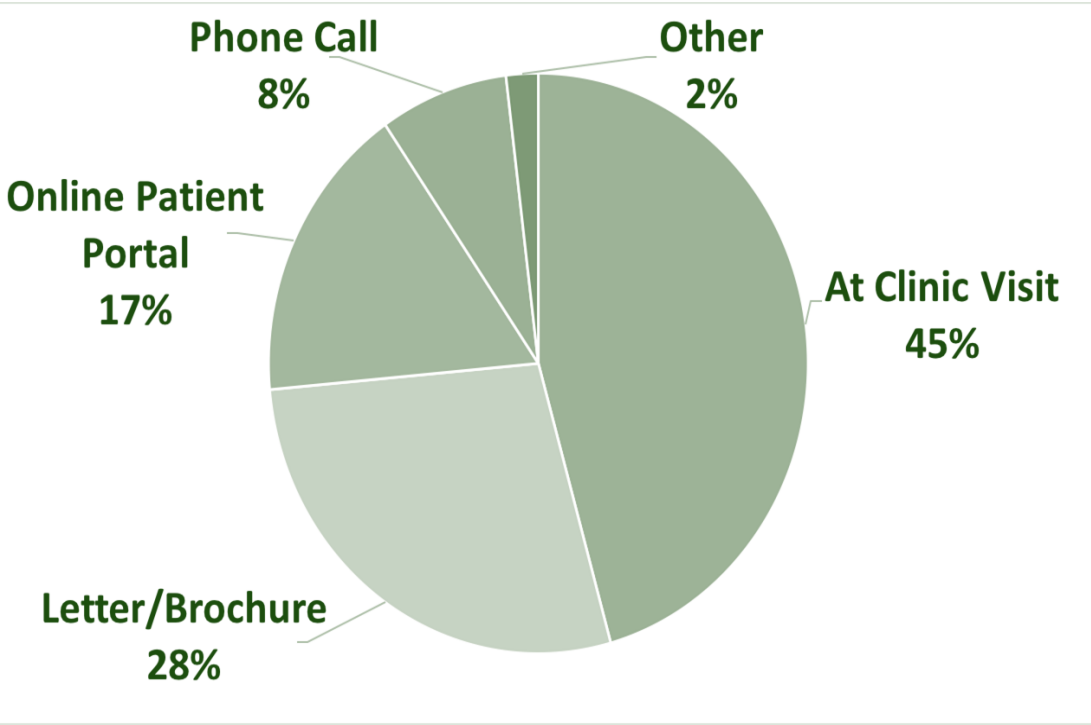
Percent of families who received normal newborn blood spot results at each clinic



Method by which newborn blood spot results were received



- Currently, there are variable practices for delivering normal blood spot results between clinics as well as between providers at the same clinic
- Normal blood spot results are not always communicated to families

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The provision of normal newborn blood spot results by primary care providers:

What's working

- Having a designated person responsible for ensuring normal NBS results are in chart before 2-week well-child visit

- High continuity of care between midwives and providers at same clinic increases likelihood that normal results are in patient chart by 2-week well-child visit

What's not

- Requirement for patients to sign a release form before NBS results are retrieved by clinic delays result reporting **(*this isn't necessary!*)**

- Lack of standardized/accurate materials in multiple languages precludes many families from understanding their child's results

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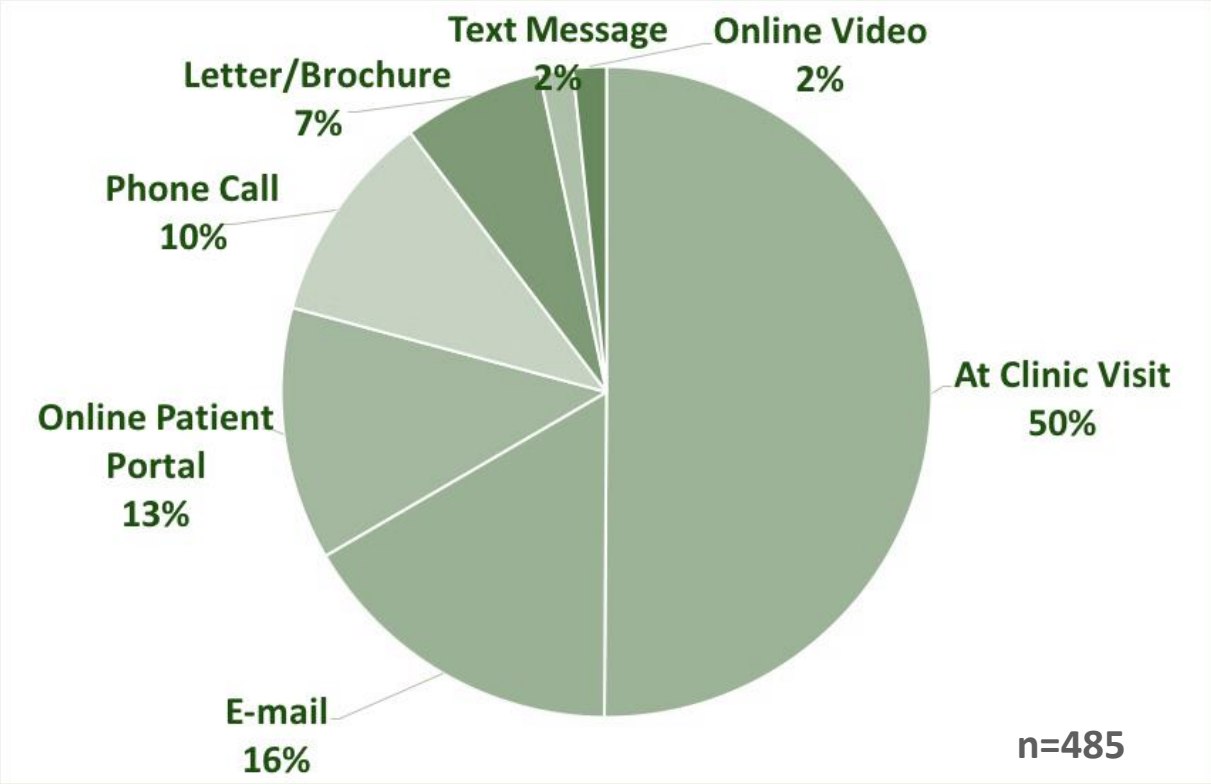
How do families feel about their experience with receiving normal blood spot results?

Preferred method to receive normal newborn blood spot results



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Primary care provider role in normal newborn blood spot result communication

Ensure that screening results are obtained and documented for all patients prior to their first well-child visit

- Ideally by 2-week visit and no later than 2-month visit

Newborn screening results should be available by the first well-child check and provided to all families, regardless of results

Primary care providers are often the ONLY way parents receive their child's newborn screening results and clear up misconceptions about this screening test

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Parent comments from survey:

- *"No, I didn't receive any results. Assume that **no news is good news**! ☺"*
- *"Pediatrician briefly mentioned my son's results came back 'good.' It could be shared at appointment in better detail with a copy of results (PDF or paper). I'm not even sure what blood type my son is."*
- *"My understanding is you only receive results if they are abnormal - this seems sufficient to me."*
- *"I don't know if I ever received my child's newborn screening results. Since I don't remember getting anything I assume all is fine. However, the fact that I'm not sure I got results is a problem."*

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Normal blood spot results fact sheet

Developed based on parental survey feedback of current practices with normal blood spot results

Aids the conversation about normal results by primary care providers

Answers common questions and misconceptions about screening

Incorporates the state's current screening panel (on back)

Provides a resource for families to reference at any point after the conversation

Prompts parents to remain vigilant about child's health despite normal screening result

Reaches a broad audience via translation into multiple languages

Normal Results:
Blood Spot Screen Results Notification

Your baby had NORMAL newborn blood spot screening results.

The newborn blood spot screen was normal (also known as 'negative' or 'in-range') for the disorders on the Minnesota newborn screening panel. This means that **your baby is at low-risk** for having one of these conditions.

This sheet will help explain what newborn blood spot screening is and what it means for your baby to have normal screening results.

What is Newborn Blood Spot Screening?

Newborn blood spot screening is done by taking a few drops of blood from your baby's heel when your baby is between 24 and 48 hours of age. Sometimes this test is called the "heel stick" or the "24-hour test." These drops of blood are sent to the Minnesota Newborn Screening Program to be screened for over 55 conditions.

Why is this screening important?

Newborn blood spot screening helps find babies at risk for certain serious disorders, so treatment can be started right away. These conditions can be found in any family - even families without a family history of these conditions. In most cases, these babies look healthy at birth, so newborn screening is often the only way to tell whether a baby is at risk.

What happens next?

Your baby's results show that your baby is at low-risk, so no more testing is needed. But, if you have any more questions about newborn screening, follow-up with your baby's healthcare provider.

Could my child have a disorder on the panel, but have a normal result?

Yes, but this is very unlikely. Because newborn screening is not a diagnostic test, a child with a condition on the screening panel may not be identified by screening (this is known as a "false negative" result). While newborn screening looks for serious, treatable conditions, it does not test for all health problems. Further testing should be done if your child shows any health problems even if the newborn screening results were normal.

You know your child best - if you have any health concerns, it is important to contact your baby's healthcare provider right away.

Resources

Baby's First Test: www.babysfirsttest.org

MN Newborn Screening Program: **651-201-5466** or www.health.state.mn.us/newbornscreening/

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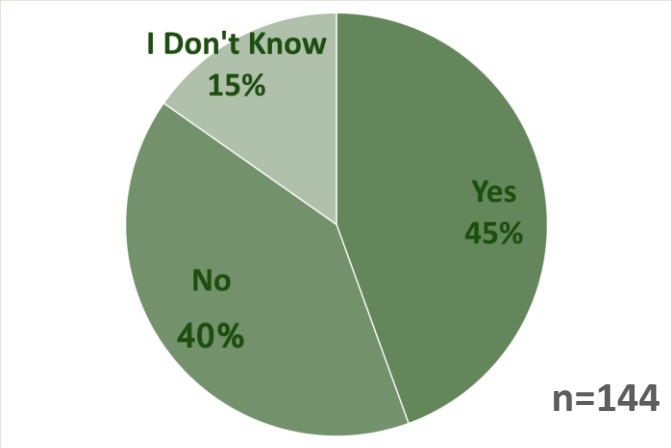
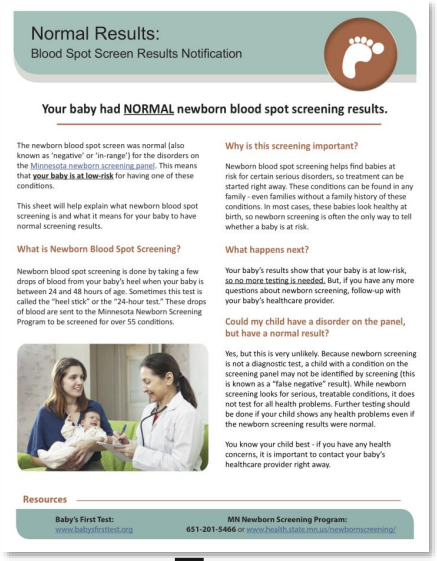
Pilot: Normal blood spot results fact sheet at two clinics

Percent of normal newborn blood spot results received by families





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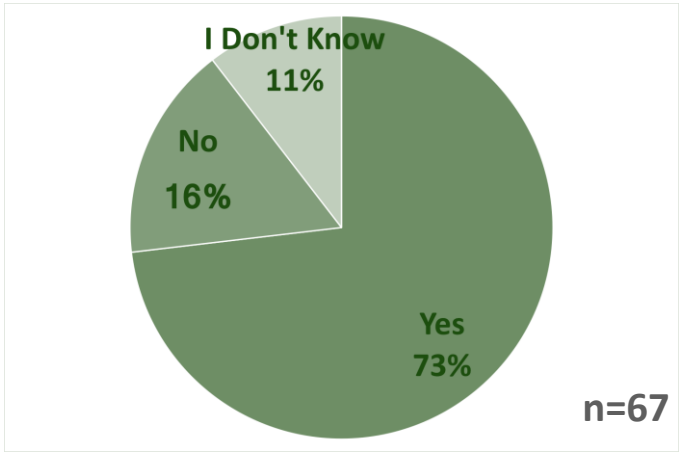

MOC4

June – November 2017

April – September 2018

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No news is ***not*** good news… no news is ***no news***

Families want their normal newborn screen results back

Your participation in this Continuing Education & Quality Improvement Project will make a difference