

Improving Communication of Negative Newborn Screening Results

Whitney Thompson MPhil

Amy Gaviglio MS, CGC

Susan Berry MD

Positive newborn blood spot results in MN

- Presumptive positive and borderline results account for 2.5% of results in MN
- Consistent and streamlined process for dissemination of positive results:
 - Program Genetic Counselors call infant's primary care provider and notify appropriate specialists
- After phone notification, an informational packet is faxed:
 - Report
 - Family fact sheet
 - Medical fact sheet
 - Specialist contact list

What happens to the other **97.5%** of results

“A ‘negative’ result means that the screen was normal for that particular disorder and no additional follow-up is required.”

-MDH website

Why do negative results matter?

“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...”*

-MDH website

False negatives in MN

1-2/year (reported)

- Most common:
 - Cystic fibrosis
 - Congenital adrenal hyperplasia
- Rarely metabolic
- Rarely of acute health impact

Leo's story

"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



A quality improvement project has been initiated to assess:

- 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
- To date (**DOB 6/1-7/15 2017**):
 - **799** surveys sent
 - **159** surveys received
 - Response rate: **19.9%**

m1 DEPARTMENT OF HEALTH NEWBORN SCREENING **Newborn Screening Results Parent Survey** 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

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

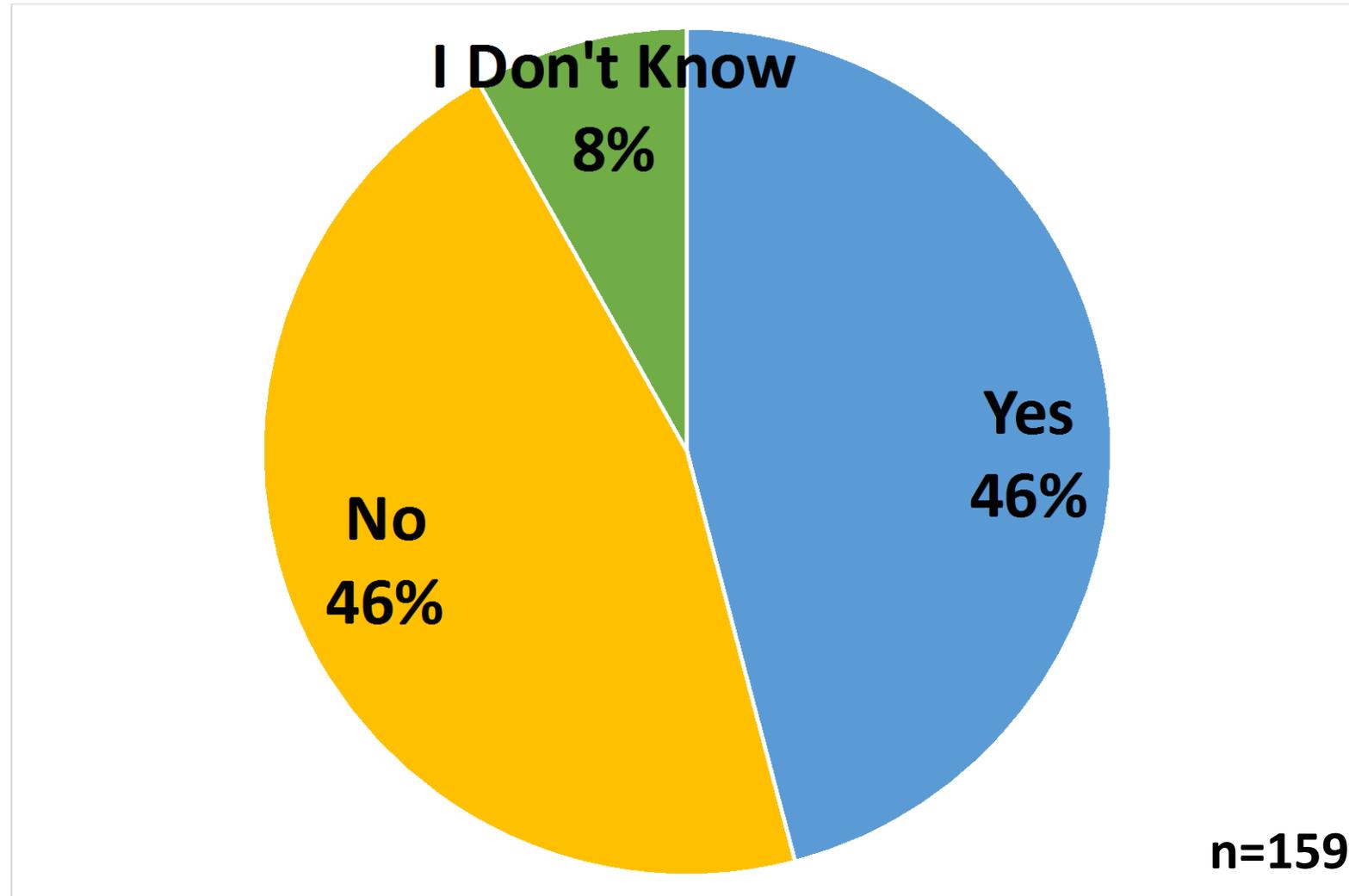
4. What is the name of your child's primary care clinic?
 Fairview Children's Clinic Partners in Pediatrics West Side Community Health
 Mayo Clinic Southdale Pediatrics Other _____

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

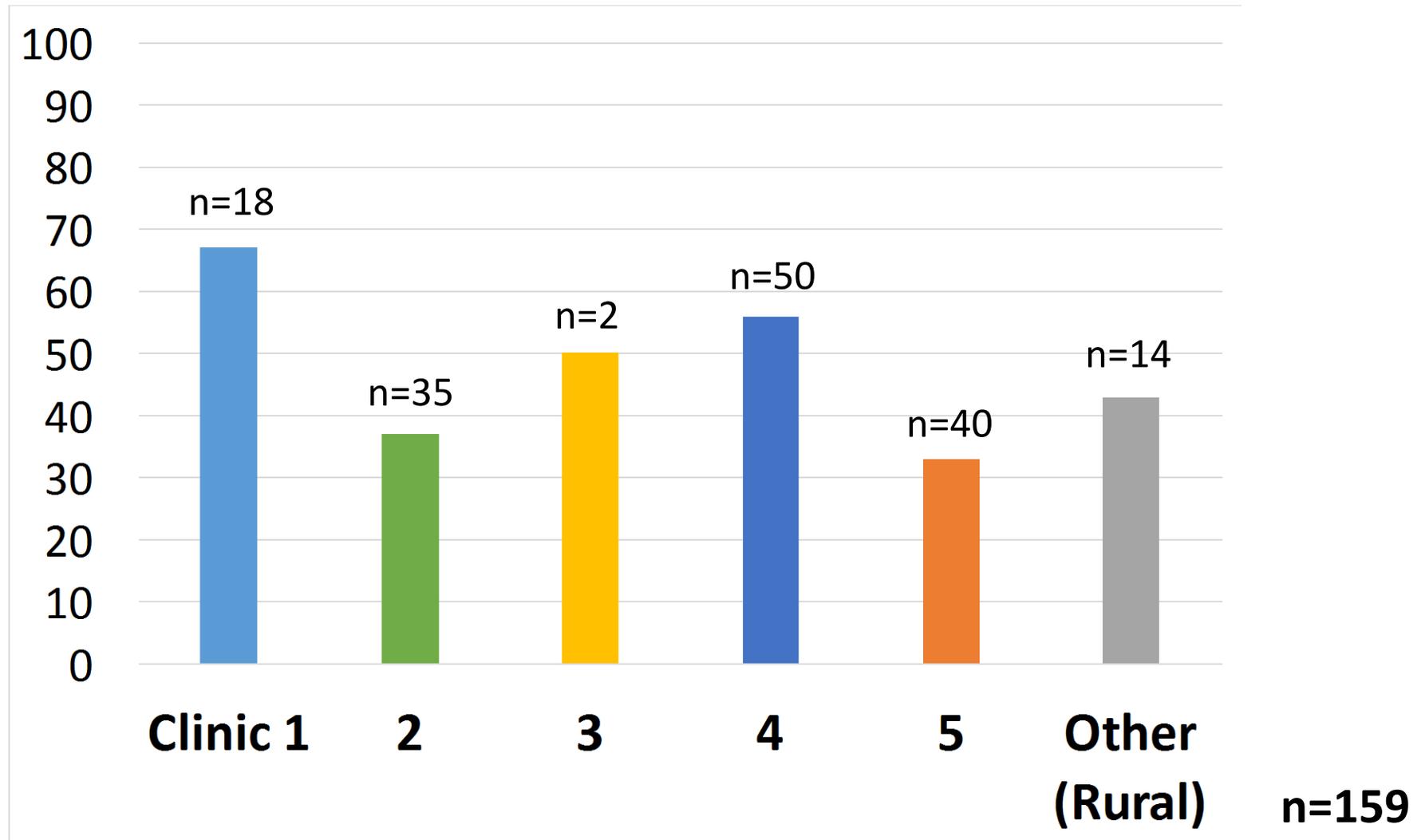
6. Were you satisfied with your experience getting your child's newborn screening results? How could it be improved?

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

Percent of Newborn Blood Spot Results Received



Percent of Newborn Blood Spot Results Received at Each Clinic



Clinics Summary

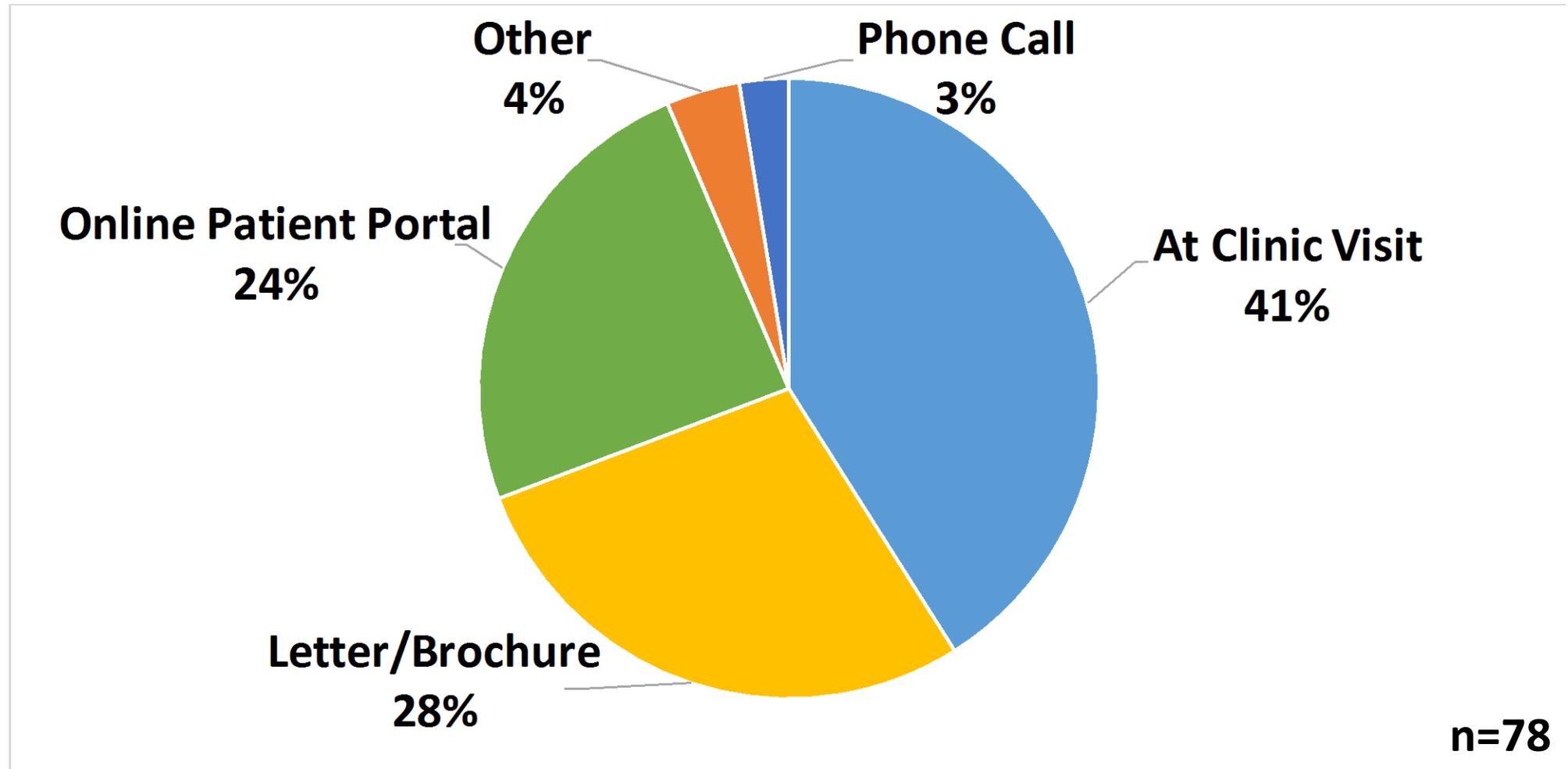
- **What's working**

- Have a designated person responsible for ensuring NBS results in chart
- High continuity of care between midwives and providers at same clinic
 - more likely to have results in patient chart by 2-week visit

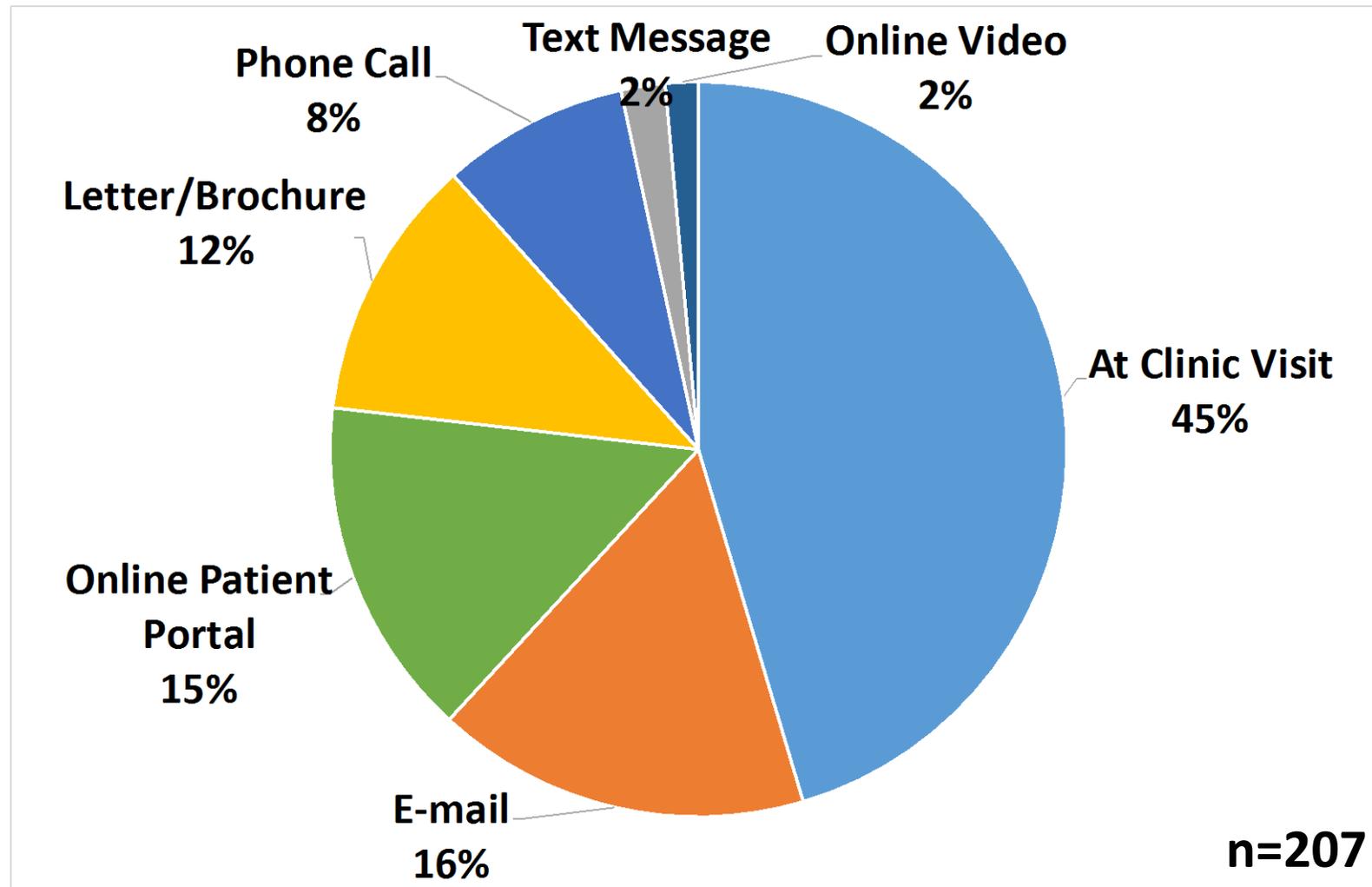
- **What's not**

- Require patients sign a release form before results retrieved
- Lack of standardized/accurate materials in multiple languages

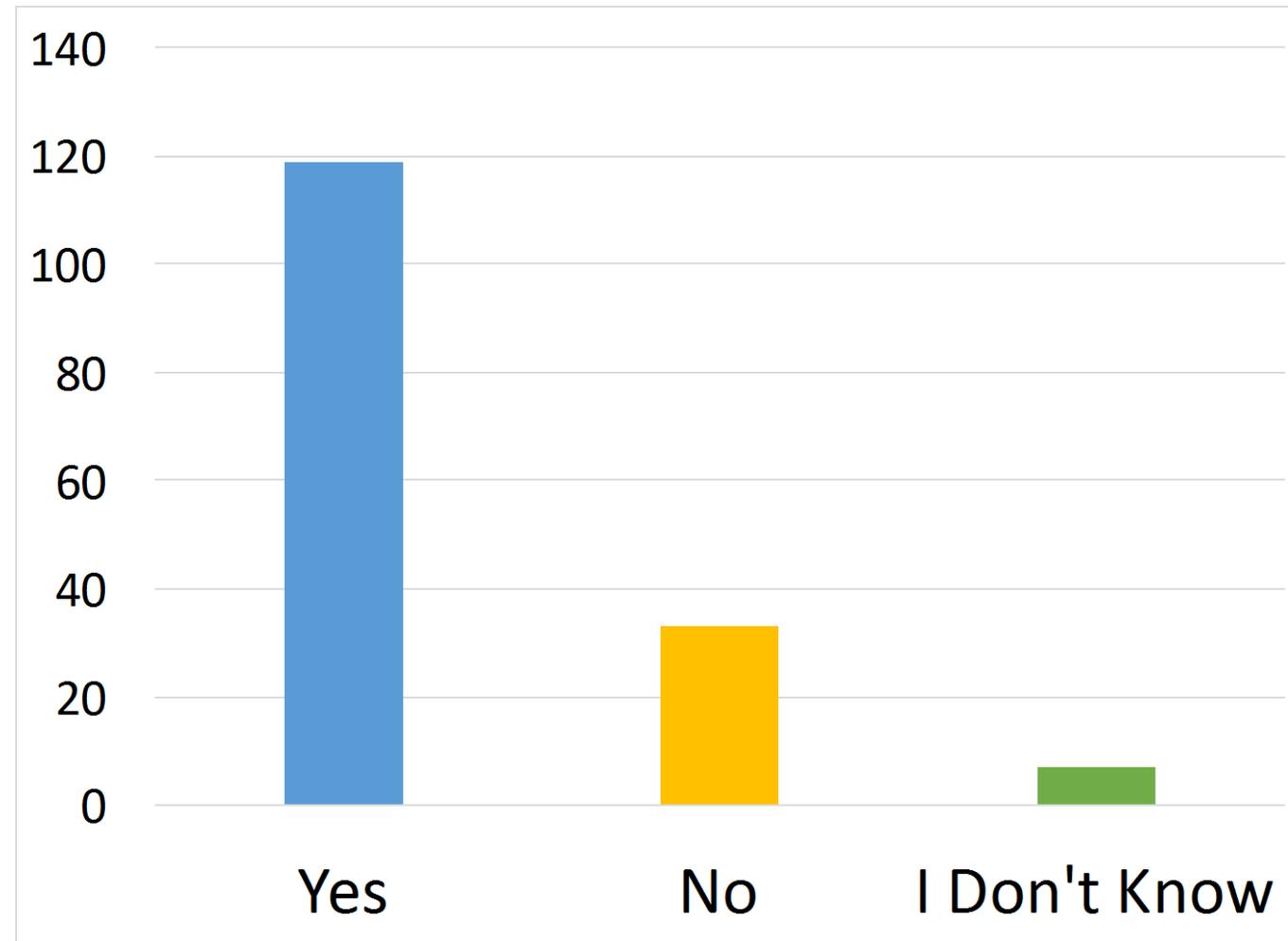
Method By Which Newborn Blood Spot Results Were Received



Preferred Method to Learn About Newborn Blood Spot Results



Reported Understanding of Screening Test vs. Diagnostic Test



n=159

Survey Question: *Were you satisfied with your experience getting your child's newborn screening results? How could it be improved?*

“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.”

*“Send out the results. The test is taken but
no one shares the results.
That's annoying.”*

“No, I didn’t receive any results. Assume that no news is good news! 😊”

“I asked about this at the 1 month check-up. Pediatrician said they received and ‘everything is normal’ but didn’t even tell me what was tested.”

“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.”

Survey conclusions thus far

- Over 50% of parents did not receive or don't know if they received their child's newborn blood spot results
- Result reporting varies widely within each clinic examined
- Most common methods of result reporting are: in-person conversation with provider, letter in the mail, and online patient portal
- Most desired method to receive results is an in-person conversation with provider
- Many parents who received results are not satisfied with the manner in which they received them and/or the lack of information they received
- Majority of parents report an understanding of screening test vs. diagnostic test

What's next

Aim: Initiate a conversation about newborn blood spot results between provider and parent at 2-week well-child visit

Development of a Maintenance of Certification course for providers detailing how to discuss negative newborn blood spot results

1 clinic in MN

- Continue assessing with parental survey
- Multiple clinics across MN
- Regional network project

What's next

“MDH Normal Result Family Fact Sheet”

- Given to parents by provider at 2-week visit when results are discussed
- Highlights limitations of screening test
- Notes symptoms parents should watch for despite normal blood spot results
- Provides resources that detail what was tested
- Translated into multiple languages

Family
Fact Sheet

Normal Results: Blood Spot Screen Results Notification

Minnesota Newborn
Screening Program



Your baby had **NORMAL** newborn blood spot screening results

The newborn blood spot screen that was collected at birth was normal (also known as 'negative') for the disorders on the MN newborn screening panel. This means that **your baby is at low-risk** for having one of the disorders on the screening panel.
No further testing is needed at this time.

What is Newborn Blood Spot Screening?

Newborn blood spot screening is done by taking a few drops of blood from your child shortly after birth. Sometimes this test is called the “heel stick” or “24-hour test.” These drops of blood are used to fill spots on a filter paper card and are sent to the MN Newborn Screening Program to be screened for over 55 rare, but treatable disorders.

Why is this testing important?

This screen is often the only way to tell whether your child is at risk for one of these disorders. If found early, infants can be treated and lead much healthier lives than if found later in life.

What happens next?

Review your child's newborn blood spot screening results with your child's doctor. Newborn blood spot screening does **NOT** detect all disorders. Screening can still miss children affected by disorders on the panel. It is important for your child to receive regular checkups with a doctor and to watch your child for health problems.



What to watch for in your child:

- Trouble breathing (very rapid or shallow breaths)
- Unusual shaking movements
- Difficulty waking up from sleep
- Severe or projectile vomiting

It is important to contact your child's doctor or the hospital right away if your child has any of the symptoms listed above.

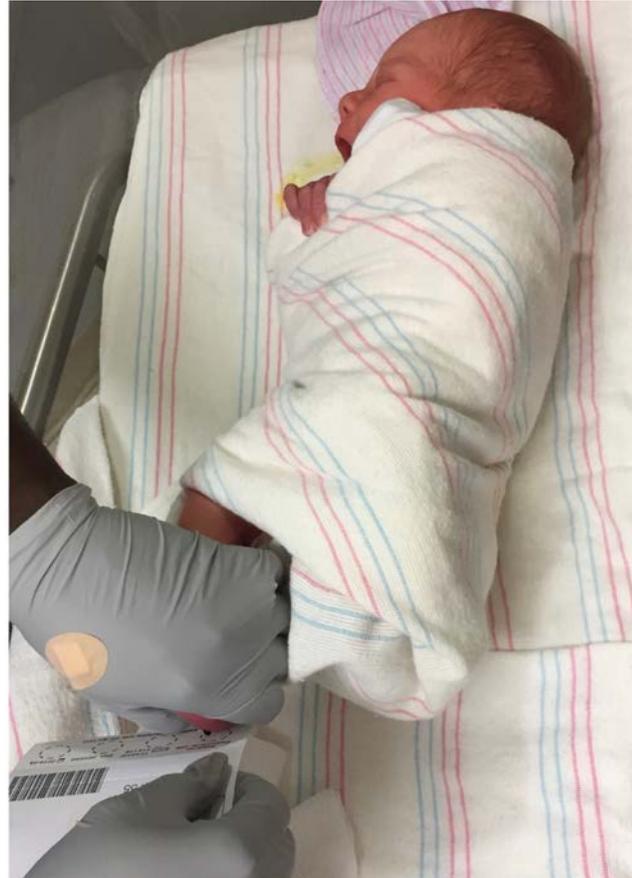
Resources

Baby's First Test:
www.babysfirsttest.org

MN Newborn Screening Program:
www.health.state.mn.us/newbornscreening/

No news is *not* good news...
It's time to start the conversation

In MN, **190** babies born/day ...



That's **190** conversations.

Comments or questions?

Whitney Thompson: thom2711@umn.edu

Amy Gaviglio: amy.gaviglio@state.mn.us

Susan Berry: berry002@umn.edu