



## Communicating Out-of-Range Newborn Screening Results to Parents and Families

**The first conversation you have with parents and families about an out-of-range newborn screening result is critical.**

Parents of newborns—especially first-time parents—are often dealing with physical and emotional changes as they adjust to their new family. Receiving an out-of-range newborn screening result is often unexpected and can lead to uncertainty.

**This guide is intended to help healthcare providers communicate out-of-range newborn screening results to parents and families. Specifically, the guide is intended to help providers:**

- **Provide** clear, accurate, and timely information to parents and families.
- **Assess** family members' understanding of this information.
- **Help** parents and families begin to navigate a wide range of emotions.
- **Empower** parents and families to take steps that can lead to positive health outcomes for their child.

You can achieve these goals by using the 4 Cs communication framework: **Clarity, Compassion, Continuity of care, and Connection.**

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## Clarity

**Help parents understand the screening result and the associated condition.**

- **Explain** to parents that their child's screening result is outside the normal range.
- **Emphasize** that the screening result is not a diagnosis.
- **Share** essential information about the condition associated with the screening result.
- **Use** parent-friendly language instead of medical jargon or scientific terms whenever possible.



### Conversation Starters

- "How familiar are you with newborn screening?"
- "Right now, this result only means that we need to do further testing."
- "Let's discuss what you need to know about this condition..."
- "Was any information I shared with you unclear or confusing?"



## Compassion

**Show empathy and validate parents' feelings, unique circumstances, and values.**

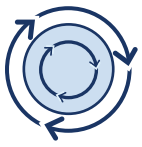
- **Be prepared** for parents to express shock, confusion, anxiety or a sense of responsibility for passing on a heritable health condition.
- **Help** parents name and describe their emotions.
- **Pause**, creating space for parents to express their concerns and questions.
- **Paraphrase** back to parents what you hear them saying to confirm your understanding of their needs.



### Conversation Starters

- "I can imagine that this may be difficult to hear..."
- "It's normal to feel a lot of different emotions right now."
- "I'm here to listen and support you and your family."
- "Thank you for helping me understand what you're feeling. I am hearing that you..."

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## Continuity of care

Help parents take an active role in their baby's care between now and their follow-up appointment.

- **Calmly convey** the urgency of follow-up testing.
- **Explain** what kind of testing will be performed.
- **Discuss** any immediate steps parents need to take as they care for their child, such as watching for specific signs or symptoms.
- **Describe** what will follow. This may include which specialists will be contacting them and when parents can expect to hear from them.



### Conversation Starters

- "We need to schedule follow-up testing as soon as possible to confirm whether your child has this condition. Will anything make it difficult for you to keep future appointments?"
- "Early diagnosis will allow your baby to get any treatment they might need as quickly as possible."
- "Contact me / my office immediately if your baby shows any of the following signs or symptoms..."
- "This is what you can expect at your follow-up appointment..."



## Connection

Reassure parents that they aren't alone.

- **Offer** to continue this conversation at the next appointment.
- **Frame** the child's care as a team effort.
- **Direct parents** to reliable sources of information about newborn screening, screening results, and associated conditions.
- **Let parents know** that other families have been through this.



### Conversation Starters

- "What questions or concerns do you have that we haven't discussed yet?"
- "The best way to contact me / my office moving forward is..."
- "I'll be working closely with the different specialists we've mentioned today."
- "I can recommend some trusted resources that can help you make informed decisions moving forward."

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## Resources to Consult and Share with Parents

[The Newborn Screening Information Center \(NBSIC\) website](#), hosted by the U.S. Department of Health and Human Services (HRSA), features the following resources:

- Comprehensive and regularly updated information about [health conditions](#) that newborn screening can identify.
- A glossary containing [plain language definitions for more than 250 terms](#) associated with newborn screening.
- Links to [educational resources for providers](#), including condition-specific ACTION (ACT) sheets and accompanying algorithms developed by the American College of Medical Genetics and Genomics (ACMG).
- Information about what parents can expect when [consulting the different specialists who perform follow-up testing](#).
- Information about and links to [federal agencies, state newborn screening programs, professional and medical organizations, and support/advocacy organizations](#).



Scan the QR code to visit the Newborn Screening Information Center website and learn more!

*Thank you to the health care professionals and parents who provided valuable feedback on and helped shape this guide.*