



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.

Continued



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.

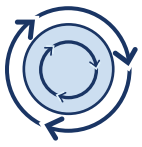
- **Be prepared** for parents to express shock, confusion, anxiety or a sense of responsibility for passing on a heritable health condition.
- **Help** parents name and describe their emotions.
- **Pause**, creating space for parents to express their concerns and questions.
- **Paraphrase** back to parents 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..."

Continued



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.