

# How Newborn Screening Results are Communicated to Providers

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# Typical Results Reported to PCP

By the NBS Program:

- Obtain a repeat screen due to sample quality issues
- Obtain a repeat screen due to early collection/transfusion/prematurity/low gestational weight
- Obtain a repeat screen due to borderline/indeterminate results
- Recommendations for further testing due to a presumptive positive result
- Carrier/trait status
- False Positive (when repeat screen is normal)

By specialist/referral center/CF Center:

- Confirmed or Ruled Out

# Communication Methods

- Mail
- Fax
- Email
- Verbally
- Electronic Communication System (between program staff; such as lab, follow up, specialist)
- Web Portal
- Or a combination of any of the above

# Communication Methods Can Vary

- Time Critical Disorders – most often are called out to the PCP by programs
- Repeats Screens – varies based on why a repeat screen is needed
- Level of Communication and Follow Up – can vary depending on infrastructure
- Type of Result – some states report carrier/trait status
- Normal results – often mailed to the birthing facility or the PCP (or communicated electronically through HL-7, web portals, etc.). No direct contact by follow up staff.

# Reporting Results

## Newborn Screening

- NBS results can be “sanitized” when communicated to the physician when entered in EHRs
- NBS results can be complex, in particular when there is second-tier testing in the screening context
- Most NBS disorders are rare - PCPs may have varying levels of familiarity
- Ordered by a provider at the birthing hospital/facility or midwife – results are reported to the PCP way of the birthing hospital or other mechanism (electronic reporting system)
- Potential for false positives in NBS – diagnostic testing required

## Diagnostic Test

- Diagnostic test results generally provide a numeric value and a reference range
- PCPs may have more familiarity with the diagnostic tests they are ordering
- The PCP or health care provider that ordered the test receives the results back

# Strategies for Communicating Complicated Results

- Verbal conversation between NBS program personnel and the PCP.
- Written recommendations and educational materials (ACMG ACT sheets or similar tools) to help explain results/disorders
- For unusual cases, some programs are able to have their lab or medical director, or the specialists/MD consultants call the PCP directly

# Challenges Regarding Communicating NBS Results to Parents

- In general, NBS programs report results to infant's PCP – it is then up to the PCP to communicate results to the parent(s).
  - Sometimes this communication is coming from clinic staff
- Not always using the same terms
- The person communicating the result may not provide specific information
- NBS programs may provide educational materials, but they may not always be used
- Information is lost in translation

# Summary

- Communication methods with PCPs often vary by severity of disorder
- Communication strategies can vary depending on program infrastructure
- Consistency in communicating information is important