Plain Language Recommendations for Reporting Newborn Screening Results

By law, lab results must be reported to anyone receiving testing and the individuals they legally represent. People undergoing laboratory testing are encouraged to review their reports, including newborn screening results. With this in mind, newborn screening lab reports must be understandable to parents and families. While some aspects of these reports may be difficult to change due to regulatory requirements, when an opportunity comes to make edits, these recommendations serve as a guidance document to create clear reports.

1. SUMMARIZE THE RESULTS

Screening results should be concisely and simply summarized

- As more diseases are added to screening panels, reports become more complex - summaries are useful to highlight key information.
  - List key information and immediate action items
  - Include appropriate contact information for follow-up questions
  - Be clear when further follow-up is necessary

See below for examples of summary text:
- This screen showed high risk for [CONDITION NAME]. Please take this child for immediate further testing. This screen showed a low risk for all other conditions.
- This screen was low risk for ALL CONDITIONS. No further action is needed at this time. Should this child develop any health concerns, a healthcare provider may suggest diagnostic testing.

2. LANGUAGE RECOMMENDATIONS

Clearly and concisely state the meaning of results

- Writing should be at or below an 8th grade reading level.
- Use the Federal Plain Language Guidelines to learn to write in plain language: [https://www.plainlanguage.gov/guidelines/](https://www.plainlanguage.gov/guidelines/)

Alternatively, use plain language software such as:
- Visible Thread Readability
- Readable.io

- Include a noticeable disclaimer stating that false negatives can happen in newborn screening. Example: "In very rare cases, a child with a condition on the newborn screening panel may not be identified by the screen."

3. RISK TERMINOLOGY IS RECOMMENDED

Move towards risk terminology

- Include specific language about high risk conditions or if all results are low risk:
  - Use high risk, indeterminate risk (borderline), and low risk.
  - The terms "positive" and "negative" can be confusing and imply diagnostic testing. These terms should only be used if the results are considered diagnostic - further follow-up is necessary for any result not considered normal.

- Terminology should always be clearly explained.

4. DESIGN RECOMMENDATIONS

Abnormal results should stand out from other results

- Highlight, change the font color, CAPITALIZE, underline or bold important points
- Place summaries and action steps before any other results so the eye goes there first. Some parents won’t read the whole report.
- If there is a trailer/footnote at the bottom of the results page, make sure any important information stands out.
- If analytes are listed, use a table and clearly state the risk profile of each condition in a column next to the analyte.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Analyte</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Galactosemia</td>
<td>Gal-1-Phosphate Uridyl Transferase</td>
<td>High Risk of Condition</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>Immunoreactive Trypsinogen</td>
<td>Low Risk of Condition</td>
</tr>
<tr>
<td>Hypothyroidism</td>
<td>Thyroid Stimulating Hormone</td>
<td>Indeterminate Risk (Rescreen)</td>
</tr>
</tbody>
</table>