Quality Improvement of Follow Up Strategies Using Region 4 Post Analytical Tools to Evaluate VLCADD and CACT/CPTII Newborn Screening Results

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What's the problem?

Time period for this project: 1/1/12 – 3/6/14

2 years and 2 months

- **122 positive screens for VLCADD**
- **125 positive screens for CACT/CPTII**

Outcomes of those positive screens:

- **VLCADD: 9 (PPV 7.3%)**
- **VLCADD carriers: 14**
- **CACT/CPTII: 0**

- **Large numbers of false positive results and the associated follow up cause the following for NBS staff, parents and other healthcare providers:**

Time analysis

VLCADD

- **Average amount of time follow up spends on the initial report of the abnormal results per case:**

38.5 minutes

- **Min:9**
- **Max: 120**

CACT/CPT2

- **Average amount of time follow up spends on the initial report of the abnormal results per case:**

71.9 minutes

- **Min: 26**
- **Max: 180**

These figures are based on a subset of the abnormal results and not the entire data set.

Time Analysis

Disorder	Average time per case	number of positive screens	Average total time spent
VLCADD	38.5 minutes	122	78.3 hours
CACT/CPTII	71.9 minutes	125	149.8 hours

- **1.1 working days per month**
- **Does not include:**
  - **repeat contacts to pediatrician**
  - **time spent discussing case with geneticists**
  - **coordinating referral to metabolic clinic**
  - **the time spent by primary care and neonatology to find, assess, and test their kids**

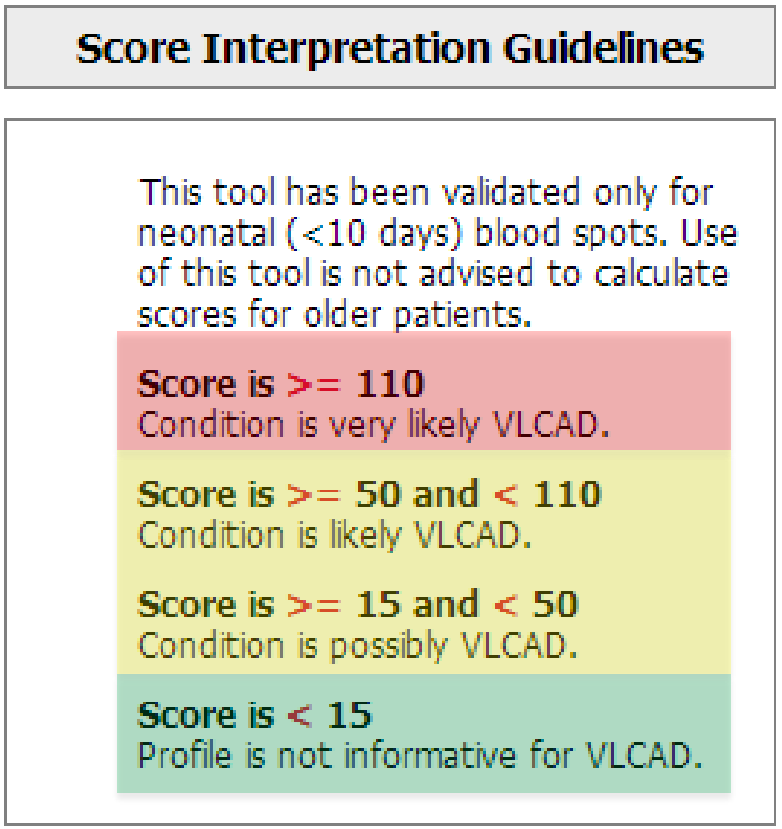
What are we doing currently?

VLCADD

- Single analyte algorithm: C14:1
- Follow up team uses R4S single condition post analytical tool
- Categorize results:
  - Low risk – repeat NBS
  - Medium risk – biochemical testing
  - High risk – biochemical and molecular testing, possible immediate referral to metabolic clinic

CACT/CPTII

- Co-primary algorithm: C16 and C18:1



Follow Up Recommendations

VLCADD

- 43 diagnostic testing
- 77 repeat NBS

CACT/CPT2

- 45 diagnostic testing
- 80 repeat NBS

Reminder of the outcomes:
VLCADD: 9
CACT/CPT2: 0

How can we make it better?

- **R4S has additional tools: dual scatter plot**
- **For this analysis we used two of these tools:**

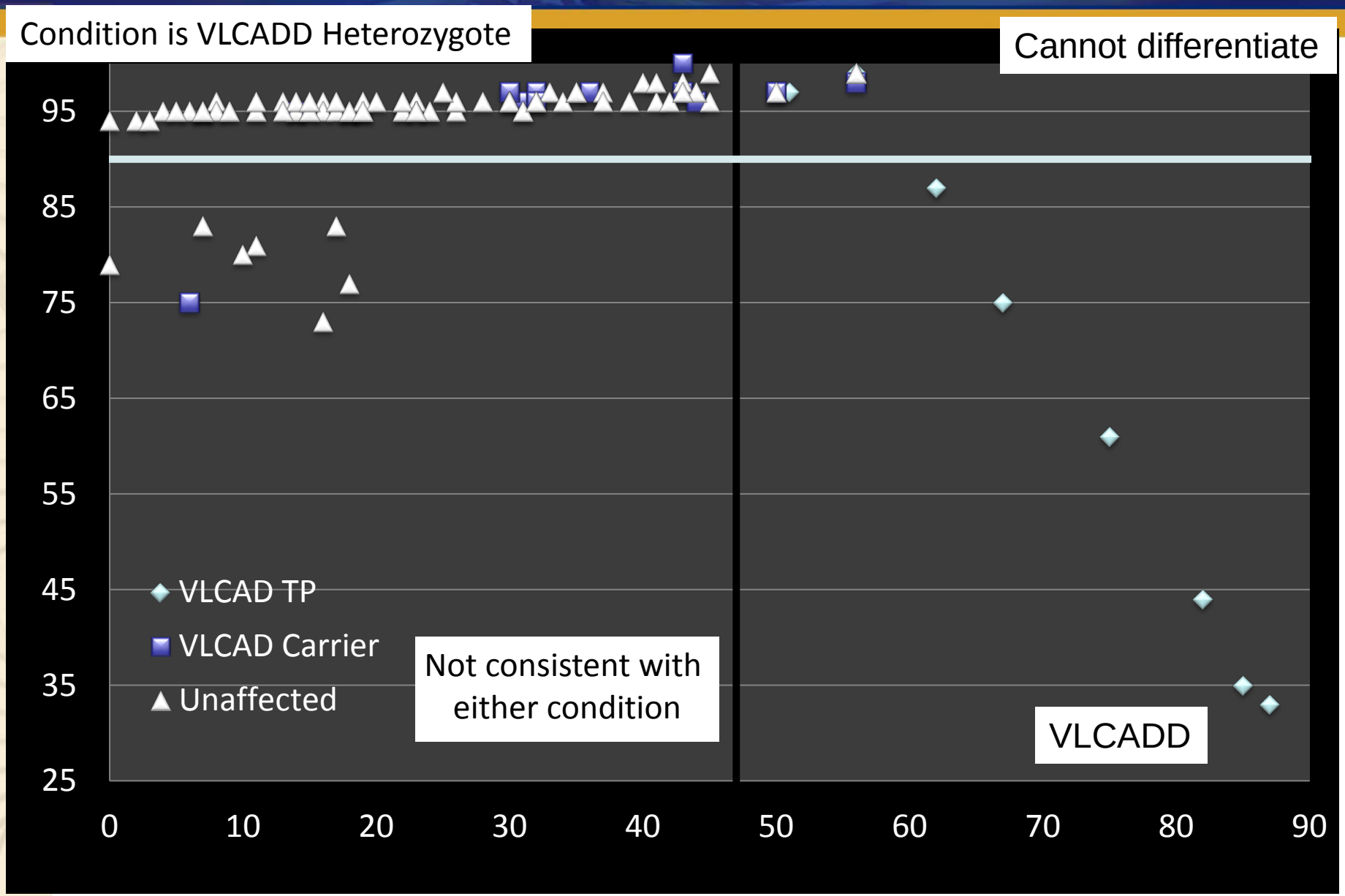
VLCADD vs. VLCADD heterozygote

CACT/CPTII vs. high C16

How can we make it better?

- Could using these tools help us determine which kids are more likely to be false positives and which kids are more likely to be affected?
- Could we use this information to reduce time spent in follow up?
- Could we reduce our false positive rate from the state lab?

VLCADD vs VLCADD Het.

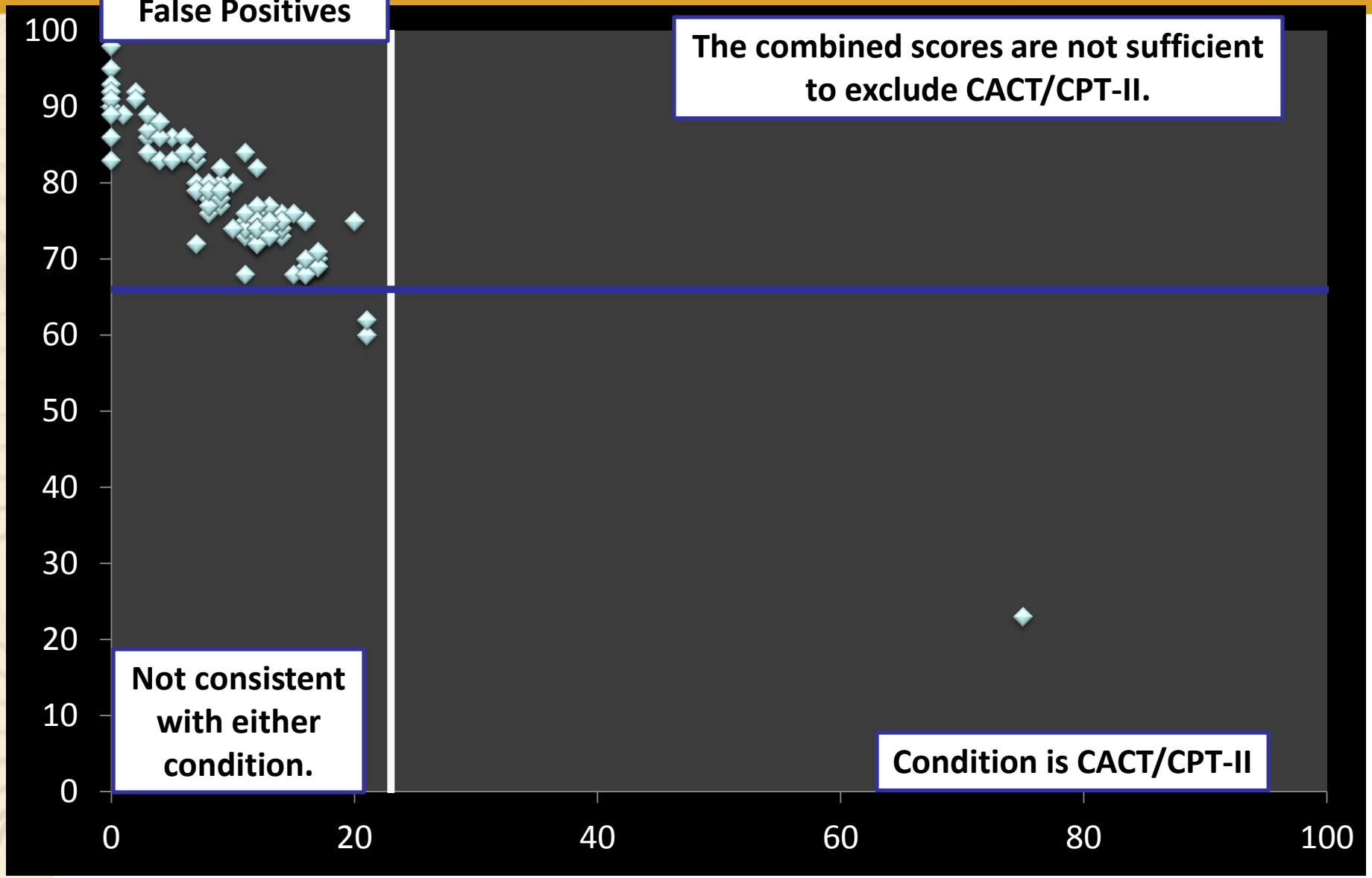


VLCADD vs VLCADD het.

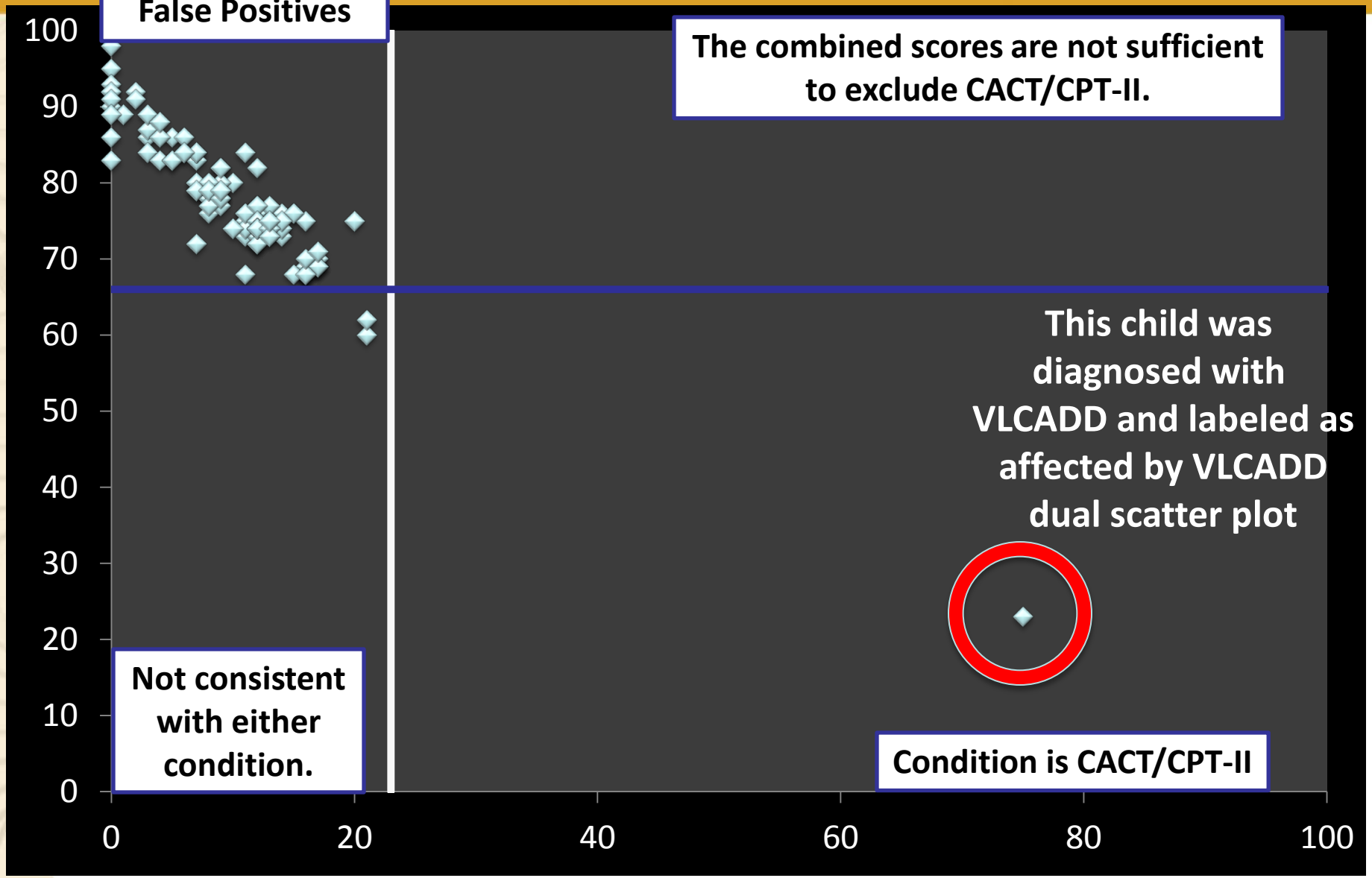
- It is reasonable to rule out all children who fall in the “VLCADD heterozygote” or the “not either condition” quadrants.

- Abnormal NBS reports and diagnostic testing are still appropriate for children who fall in the indeterminate or affected quadrants.

CACT/CPTII vs high C16



CACT/CPTII vs high C16



CACT/CPTII vs high C16

- **Confidence in making big changes?**
  - **No diagnosed cases in this group of children.**
- **Can we stop calling these positive screens?**
- **Should we take a less cold turkey approach and advise assessment then close if normal?**

Why is this important?

- **False Positive screens are a problem**
  - **Testing algorithms are stretched**
  - **Follow up algorithms are stretched**
  - **Providers are stretched**
  - **New conditions are coming: SCID, Pompe pilot, CCHD**
- **Resources are limited, demands increasing = need process improvement!**

Dual Scatter plot tools may be our opportunity to reduce workload and be highly effective

Plans and Ideas

- We will continue to evaluate these tools
- Partner with the state lab in utilizing tools
- Consider partnering with other states to evaluate tools

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