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# Clinical Surveillance Strategies Are Emerging: Building Consensus

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CHOP/IFIG, 2018



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# Background

- Ongoing stress/damage
- Multiple organ systems
- Unknown > Known



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# DEFINITIONS OF SURVEILLANCE

A Dictionary of Epidemiology, 4<sup>th</sup> ed, 2001  
(J.M. Last (ed))

**“Systematic ongoing collection, collation,  
and analysis of data and the timely  
dissemination of information to those  
who need to know so that the action  
can be taken”**

**Source: World Health Organization**



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# DEFINITIONS OF SURVEILLANCE

## KEY ELEMENTS (Detels, 1989)

1. Collection of health data expressly for use in health planning, disease control/ prevention, and/or health promotion
2. Ongoing collection of data
3. Timely analysis
4. Easily understood
5. Dissemination of results
6. Action based on results
7. Periodic evaluation of the system



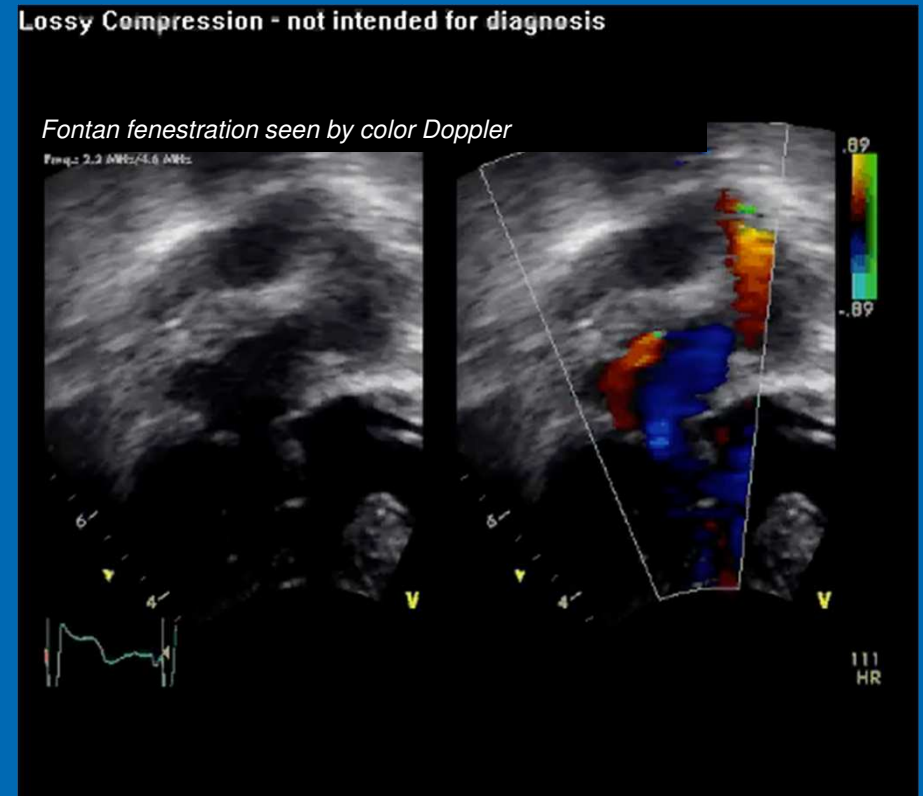
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# Colorado 2014

- Many providers & few patients
- *Practice variability*
- Inconsistent approach
- Development of a Fontan Care Program



# Fontan Program – Institutional Survey

- 10 institutions with identified Fontan Programs:

University of Michigan

Sibley Heart Center/ (Emory affiliate-Atlanta)

The Children's Hospital of Philadelphia

Mayo Clinic

Boston Children's Hospital

Lucile Packard Children's Hospital Stanford

Cincinnati Children's Medical Center

Children's Hospital Colorado

Ann & Robert H. Lurie Children's Hospital of Chicago

University of Utah



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# Fontan Program Survey: Cardiac Testing

	ECG	Echo	Holter	Exercise	Cath	cMRI	BNP
Every 6 months	2	1	0	0	0	0	0
Every year	7	6	3	1	0	0	5
Every two years	1	2	3	3	0	1	1
Less often than every two years	0	0	2	6	7	8	3
We do not routinely order this test	0	0	2	0	3	1	1



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# Fontan Survey: Other Testing

	CBC	PFT	Albumin	Liver US	Liver Bx	Cystatin C
Every year	7	1	7	1	0	4
Every two years	2	1	2	5	0	1
Less often than every two years	1	7	1	4	5	3
We do not routinely order this test	0	1	0	0	5	2



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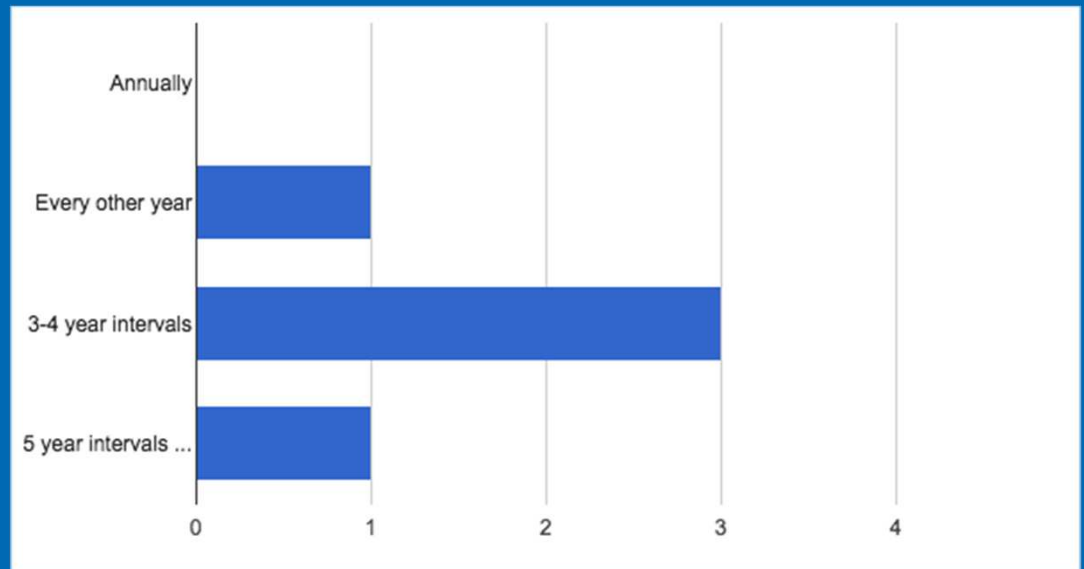


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# Neurodevelopmental

- 50% as needed
- 50% routinely →



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## International Fontan Interest Group (IFIG)

NATIONAL PEDIATRIC CARDIOLOGY  
*Quality Improvement Collaborative*



IF YOU WANT TO RUN FAST, RUN ALONE.  
IF YOU WANT TO RUN FAR, RUN  
**TOGETHER.**



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# Denver Meeting, March 2017

*Colorado, Boston Children's, CHOP, Utah, Mayo Clinic, Atlanta, Stanford,  
Cincinnati, Northwestern, Milwaukee, Michigan*

- Discuss alignment of Fontan Programs
- Surveillance matrix



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# American Heart Association (AHA)

- Statement on the Care of the Fontan – Underway



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# Fontan Expert OPINION Survey

*Adel Younoszai, MD*

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- Children's National
  - CHOP
  - Royal Prince Alfred Hospital, Sydney
  - Indiana University - Riley Children's Hospital
  - Mayo Clinic
  - Children's Healthcare of Atlanta
  - Children's Hospital of Wisconsin
  - University of Michigan
  - Children's Hospital Colorado
  - Boston Children's Hospital
  - Emory University / Sibley Heart Center
  - MUSC
  - Cincinnati Children's Hospital Medical Center
  - Children's Hospital at Montefiore
  - Lucile Packard Children's Hospital Stanford
  - Lurie Children's Hospital
  - University of Utah
- N = 28



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# Level of Importance for Testing

**Class I** = Highly likely of clinical value ...all patients with a Fontan circulation.

**Class II** = Likely of clinical value ...may not need to be performed in all patients.

**Class III** = Possibly of clinical value ...may benefit from further investigation.



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- **Young Children < 12 yr**
- **Adolescents < 18 yr**
- **Adults**



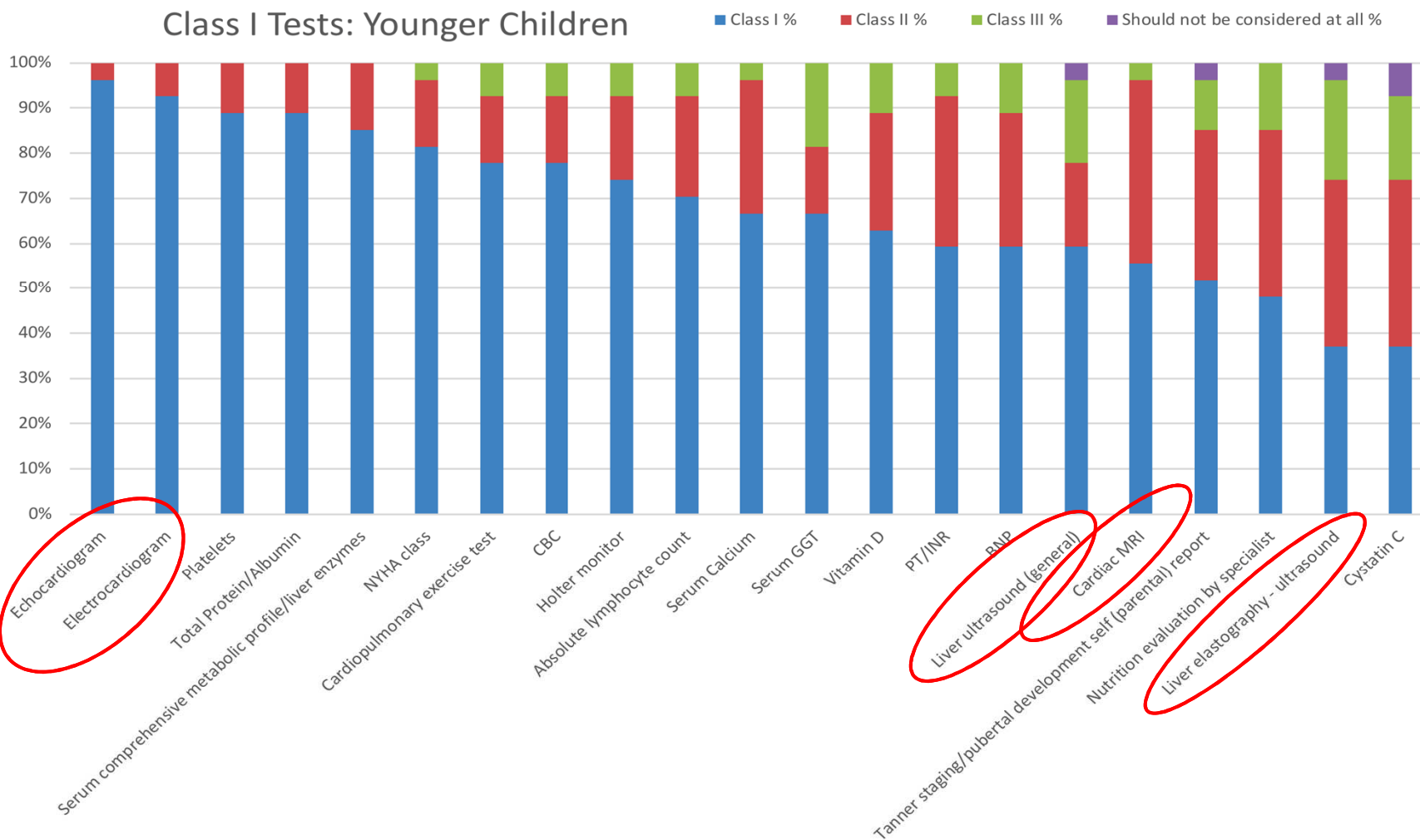
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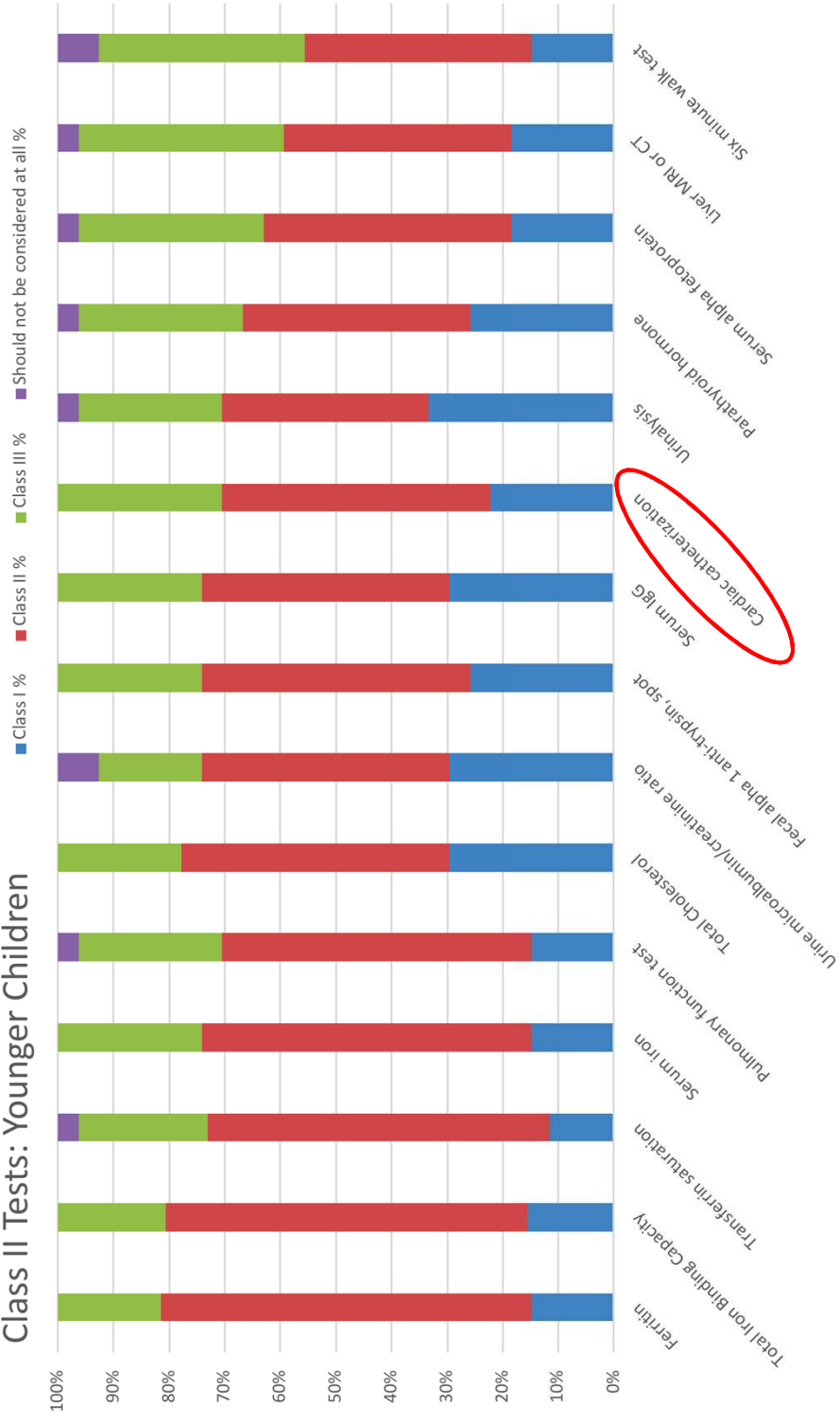
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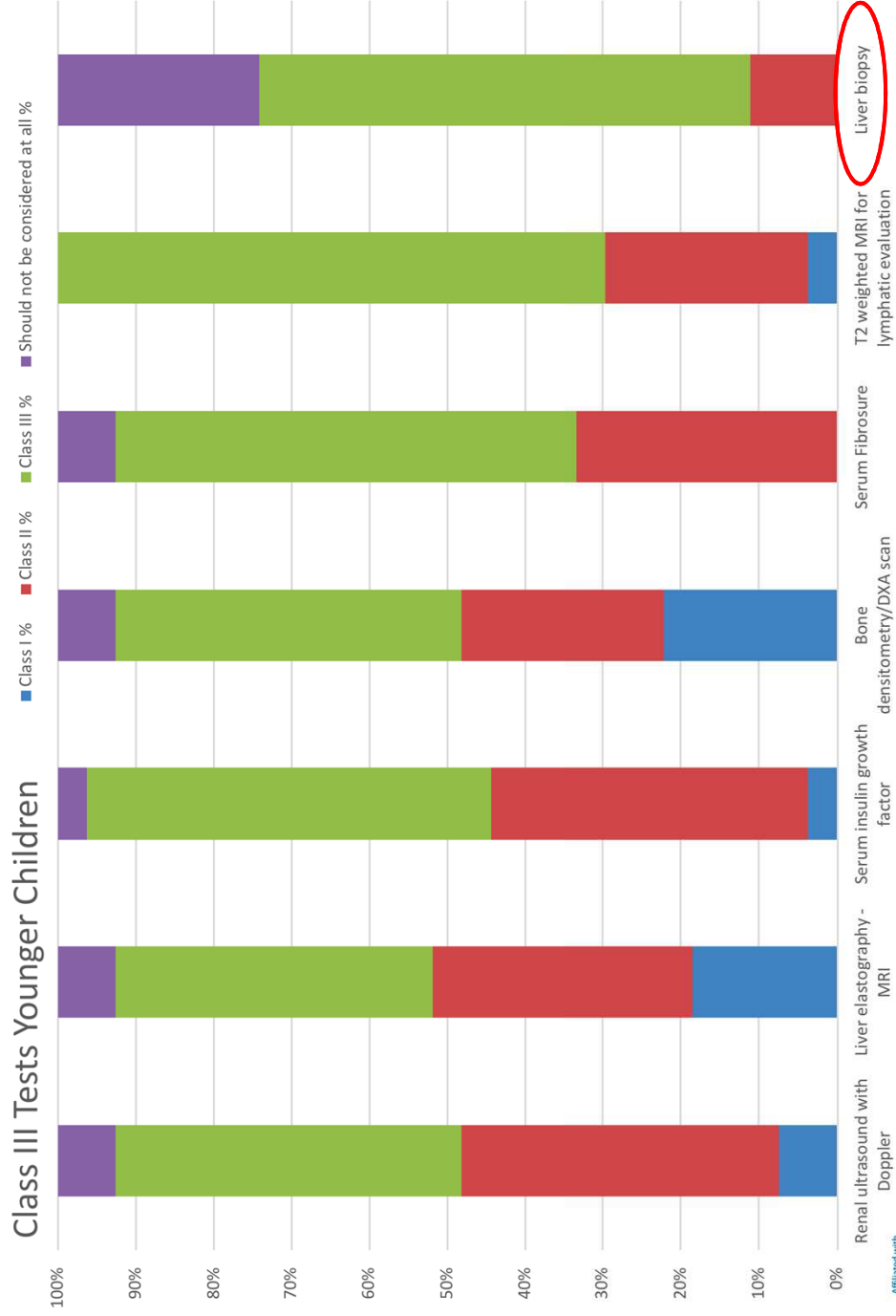


## Class I Tests: Younger Children

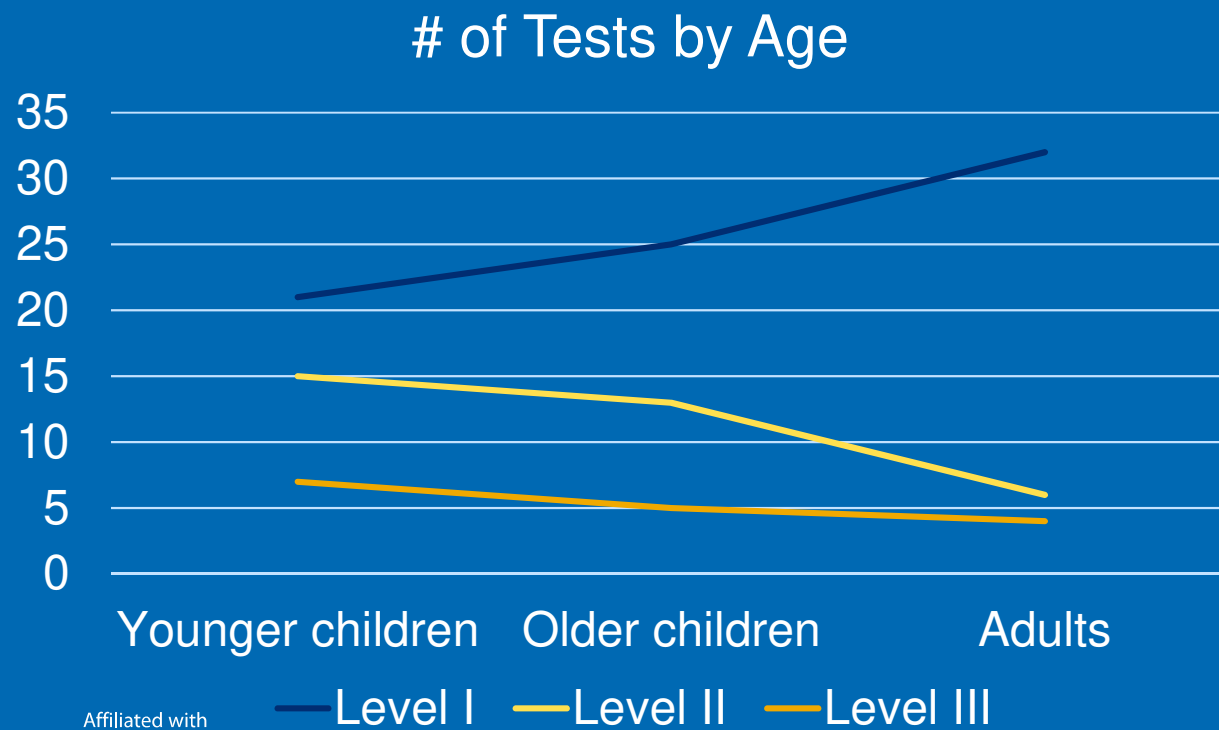


## Class II Tests: Younger Children





# Older = Closer Surveillance



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# Summary

- Surveillance = obtain/review population data
- No consensus on how to do this
- Lack of data should not paralyze us
- Recognition → Organization → Collaboration



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