Harmonizing Hearts

Embracing Variability in Single Ventricle Care

Kiona Allen, MD
Lurie Children's Hospital

Thomas Glenn, MD
Texas Children's Hospital

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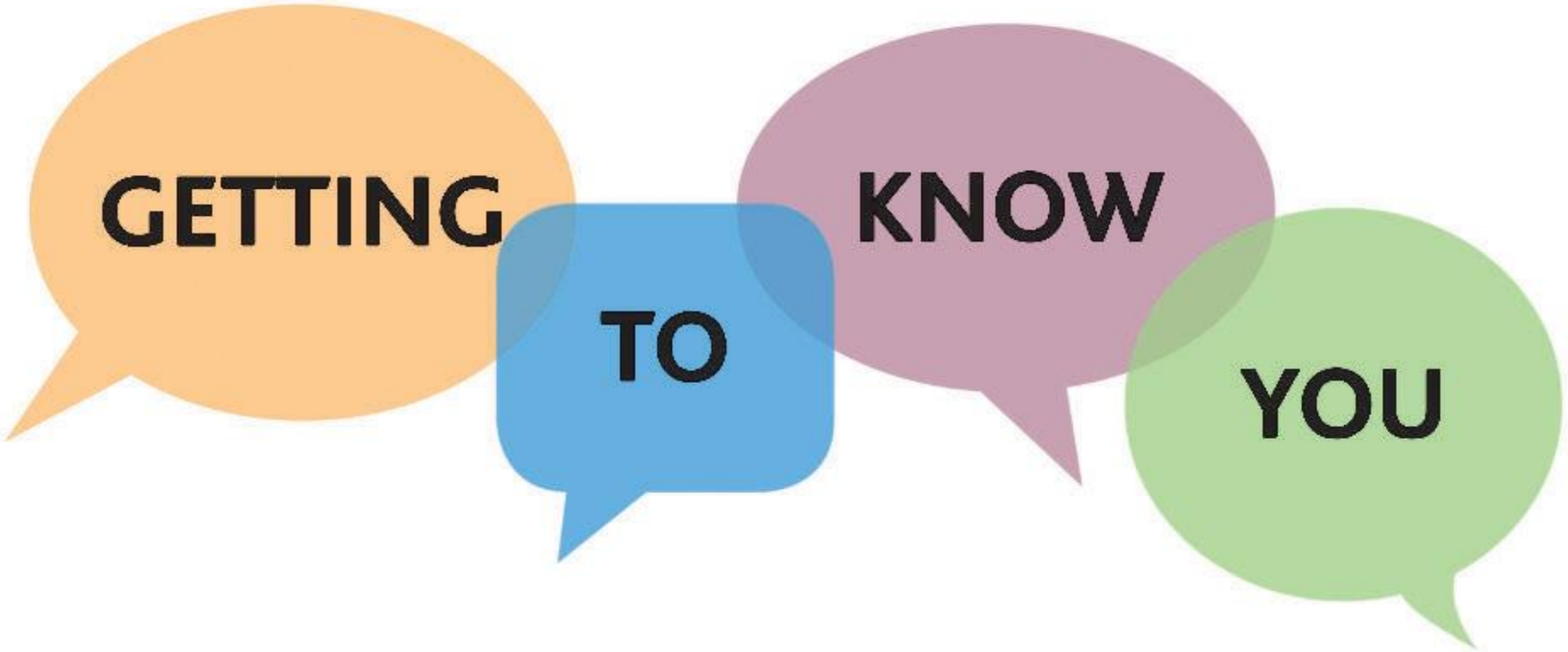
What are things like in your neck of the woods?



How would you identify yourself?

A. Patient
B. Caregiver/Family Member
C. NPC-QIC Team Provider
D. FON Team Provider
E. Provider from a combined NPC-QIC/FON Team

Do your NPC-QIC/FON Teams routinely partner on their clinical work

A. Yes
B. No
C. We are one combined team

Do your NPC-QIC/FON Teams routinely partner for research and quality improvement projects

A. Yes
B. No
C. We are one combined team

What is the makeup of your interstage team?

Select all that apply

A. Dedicated interstage cardiologists
B. General cardiologists
C. Advanced practice providers (APN or PA)
D. Nurses
E. Dieticians
F. Developmental specialists (PT, OT, Speech, Psychologists)
G. Social workers and/or care coordinators
H. Pediatricians

Does your center have a dedicated clinic for patients after the Fontan Operation?

A. Yes – and they follow the majority of patients after Fontan
B. Yes – but they only follow some of the patients after Fontan
C. Yes – for consultation only
D. No

What services are embedded in your Fontan Clinic?

Select all that apply

A. Cardiology
B. Exercise Physiology
C. Hepatology
D. Endocrinology
E. Nephrology
F. Immunology
G. Nutrition Services
H. Neurodevelopmental specialists (PT, OT, Speech, PM&R)
I. Psychology
J. Social work and/or care coordination

At what age do you routinely start with liver surveillance?

A. Immediately after the Fontan procedure
B. 5 Years post-Fontan
C. 10 years post-Fontan
D. At some point prior to 18 years of age
E. I don't perform routine liver surveillance
F. As needed, if any issues arise
G. I leave that to the hepatology team

What does liver surveillance look like for your patients with Fontan circulation?

Select all that apply

A. Liver function tests (AST, ALT, GGT, etc)
B. Serum α-fetoprotein
C. Liver ultrasound
D. Liver ultrasound with elastography
E. Abdominal (liver) CT
F. Liver MRI
G. Liver MRI with elastography
H. Liver biopsy
I. Other
J. None of the above

Is variability from center to center a bad thing?

- There is tremendous variation across programs and centers
- Goal = reduce unnecessary variation and start to identify standards of care
- Some variation may be beneficial
- Centers don’t have to be exactly the same to partner and get things done

What can we LEARN from each other?

Looking Back: Original FON Care Center Survey

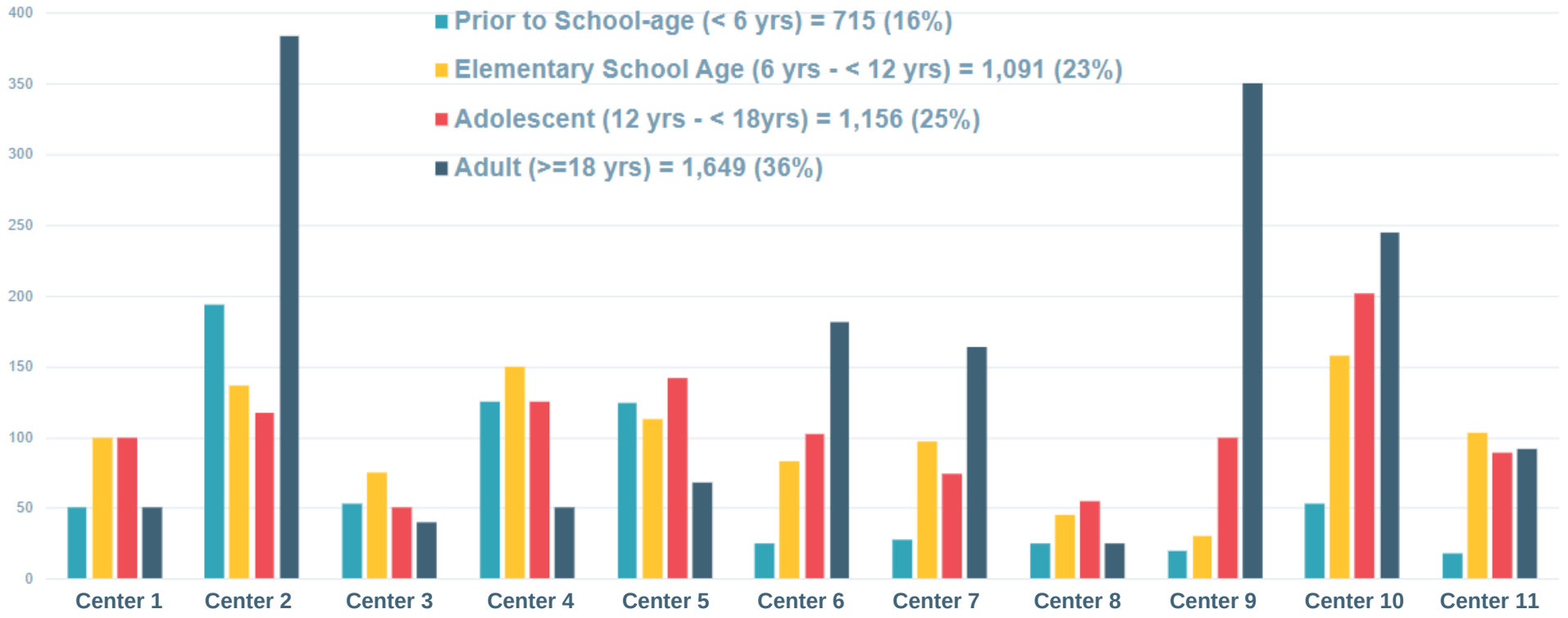
- Relatively mature NPC-QIC program focused on a discrete time period typically managed by a relatively standardized type of highly specialized team
- FON is more complex: diverse systems of care/compositions of teams with extended time period for follow-up (entire lifespan)
- Surveyed original FON “pilot” centers to assess current state
- Outcomes of survey presented in the Fall 2021 Virtual Learning Session

Core questions:

- Who are our FON patients?
- Who are our FON teams?
- What do our FON centers look like?

Looking Back: Original FON Care Center Survey

Of those individuals with Fontan circulation seen regularly at your cardiology center, about how many are in the following age groups?



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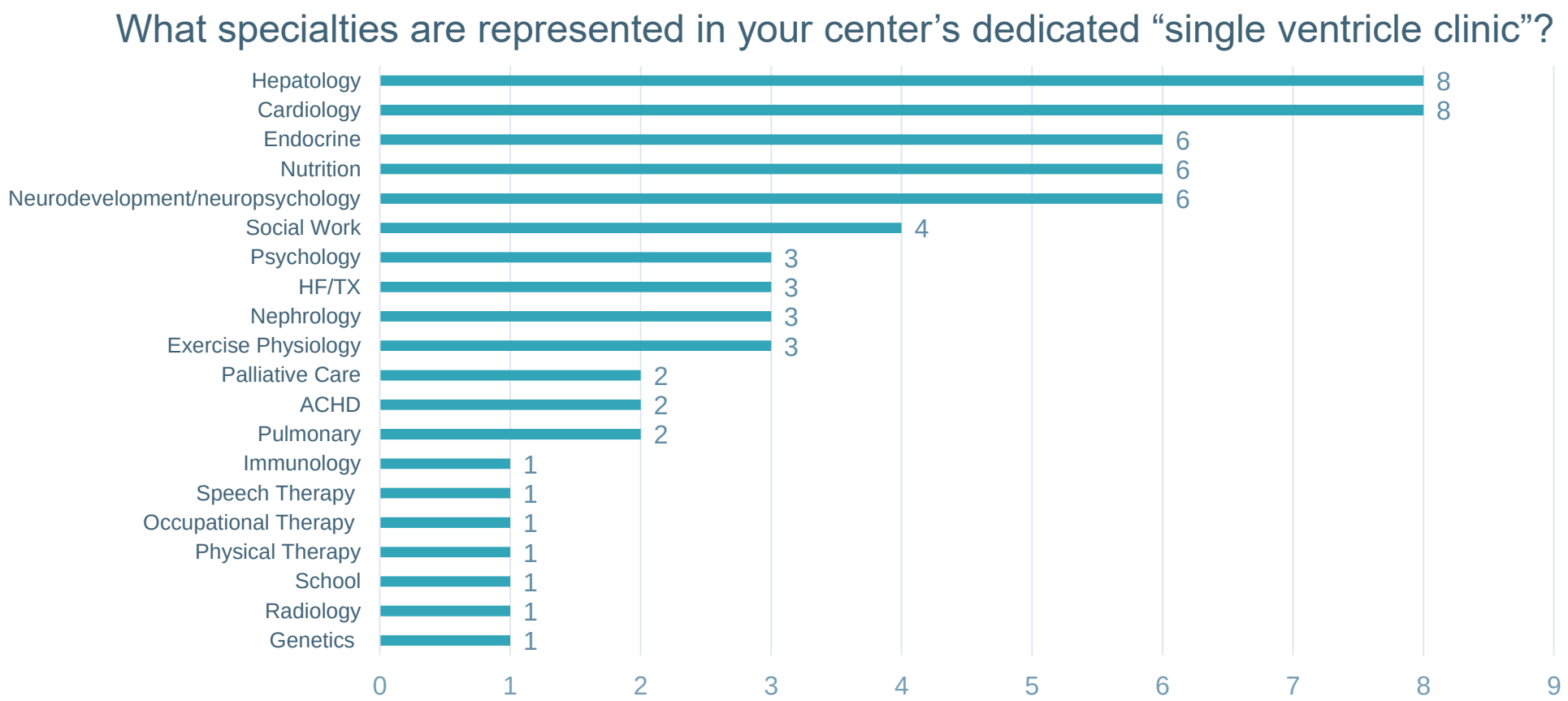
Looking Back: Original FON Care Center Survey



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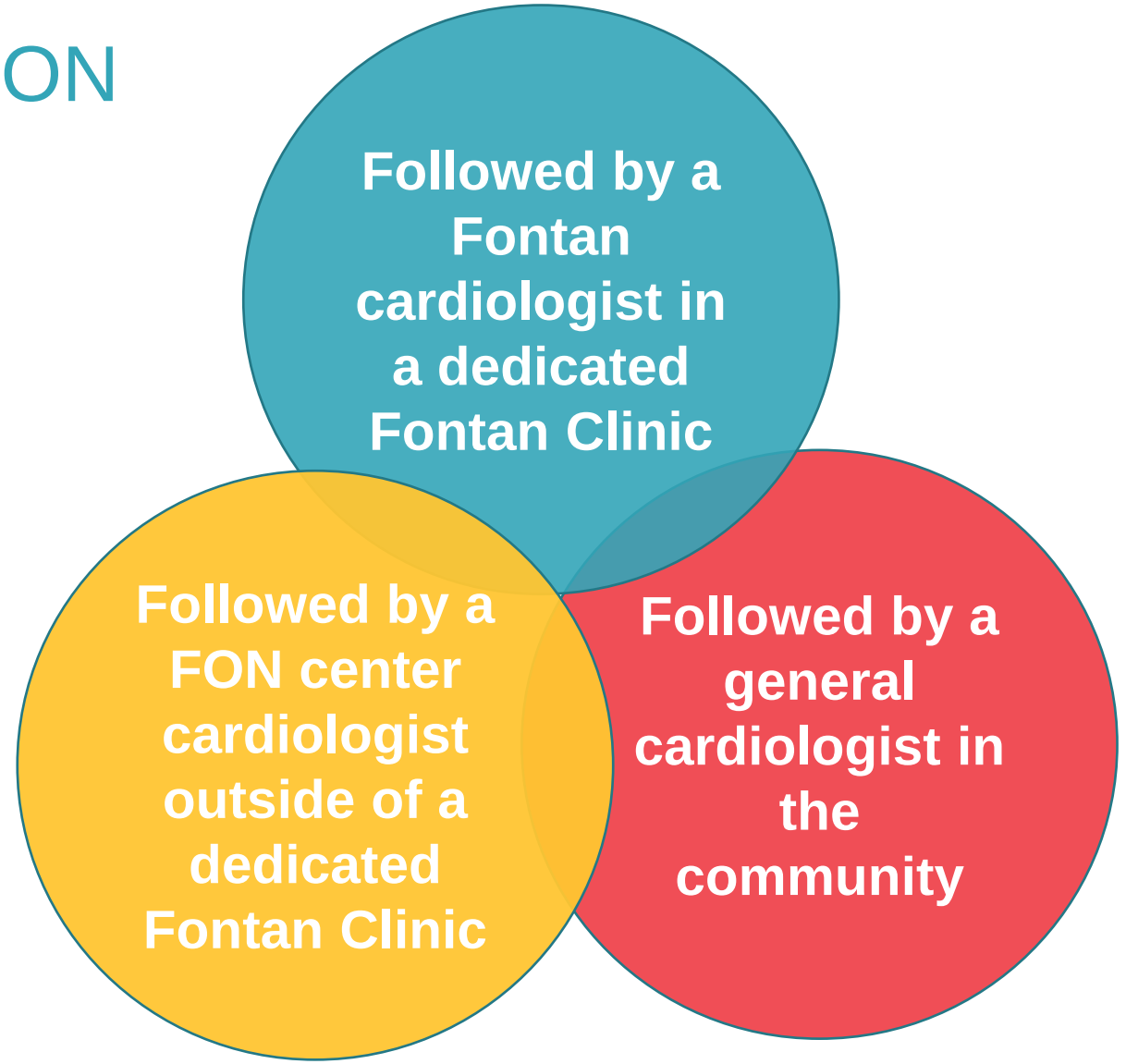
Looking Back: Original FON Care Center Survey

What models of care apply to patients followed regularly at your institution:

- **7** of **12** centers had patients who followed primarily in a dedicated Fontan Clinic
- **7** of **12** centers had patients who followed primarily outside of Fontan Clinic
- **9** of **12** centers had patients who shared care between the Fontan Clinic and general cardiology

Did not explore cardiac care provided primarily by providers outside the FON Care Center



What variation…?

Testing	Care Center 1 (Patient)	Care Center 2 (Patient)	Care Center 3 (Patient)	Care Center 4 (Provider)	Care Center 5 (Provider)	Care Center 6 (Provider)
ECG and Echo	Yearly	Yearly	Yearly	Yearly	Yearly	Yearly
Holter/Rhythm monitor	Never	Yearly	As needed	Yearly	Every 1-2 years	Yearly
Liver imaging (US or MRI)	Never	Never	Yearly	Every 2-3 years	Yearly	Yearly
Exercise Testing	Never	Never	Yearly	Every 2-3 years	Yearly	Yearly

What variation…?

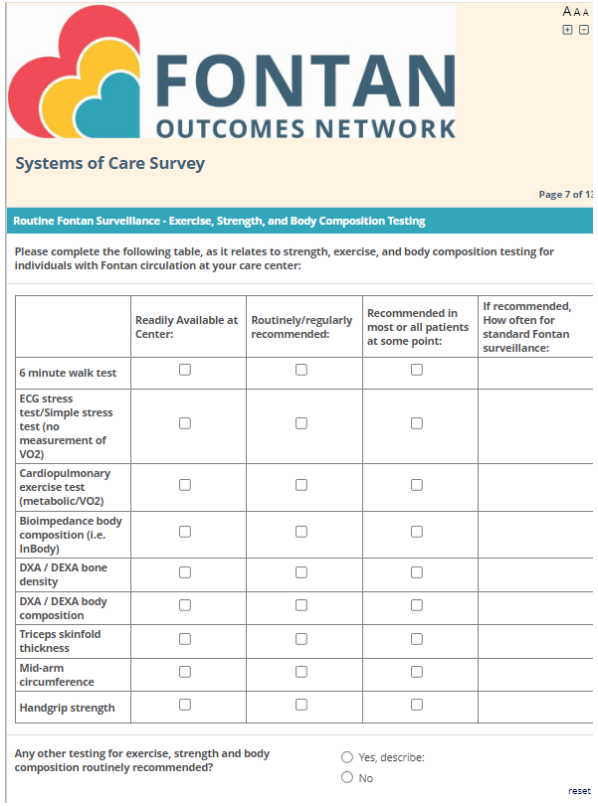
Specialty	Care Center 1 (Patient)	Care Center 2 (Patient)	Care Center 3 (Patient)	Care Center 4 (Provider)	Care Center 5 (Provider)	Care Center 6 (Provider)
Cardiology	Yearly	Yearly	Yearly	Yearly	Yearly	Yearly
Hepatology	Never	Never	Yearly	Yearly, in Fontan MDC	Yearly, in Fontan MDC	Yearly, in Fontan MDC
Psychology	Never	Never	Never	As needed	Yearly, in Fontan MDC	Yearly, in Fontan MDC
Exercise physiology/PT	Never	Never	Never	Never	Yearly, in Fontan MDC	Yearly, in Fontan MDC

Let’s take another look at Fontan care in 2024

How is Fontan care being delivered?

- Survey of all current NPC-QIC and FON sites
- Determine current practice as a WHOLE at each center
  - Survey completed by one person at each center
- We expect and welcome variety in processes and practices
- **How can we reduce unnecessary variability and how can we help one another?**
- Survey to be sent to care center leads in coming weeks

Fontan Systems of Care Inventory



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Systems of Care Survey

Page 7 of 1

Routine Fontan Surveillance - Exercise, Strength, and Body Composition Testing

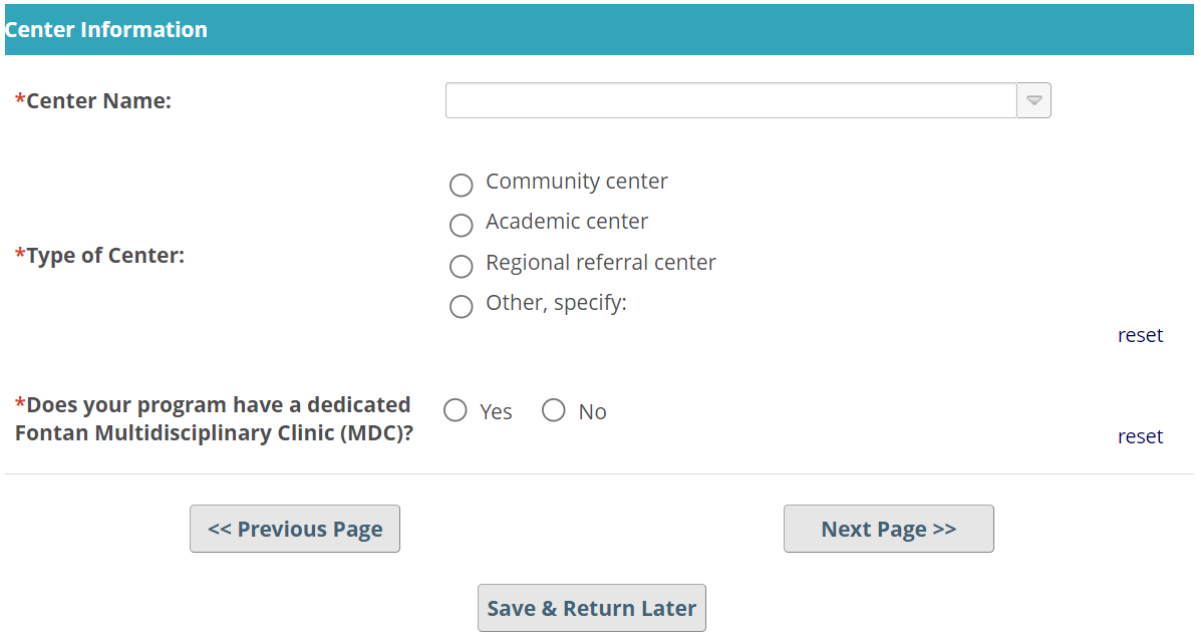
Please complete the following table, as it relates to strength, exercise, and body composition testing for individuals with Fontan circulation at your care center:

	Readily Available at Center:	Routinely/regularly recommended:	Recommended in most or all patients at some point:	If recommended, How often for standard Fontan surveillance:
6 minute walk test	☐	☐	☐	
ECG stress test/Simple stress test (no measurement of VO2)	☐	☐	☐	
Cardiopulmonary exercise test (metabolic/VO2)	☐	☐	☐	
Bioimpedance body composition (i.e. inBody)	☐	☐	☐	
DXA / DEXA bone density	☐	☐	☐	
DXA / DEXA body composition	☐	☐	☐	
Triceps skinfold thickness	☐	☐	☐	
Mid-arm circumference	☐	☐	☐	
Handgrip strength	☐	☐	☐	

Any other testing for exercise, strength and body composition routinely recommended?

○ Yes, describe:
○ No

reset



Center Information

*Center Name:

*Type of Center:

○ Community center
○ Academic center
○ Regional referral center
○ Other, specify:

reset

*Does your program have a dedicated Fontan Multidisciplinary Clinic (MDC)?

○ Yes ○ No

reset

<< Previous Page

Next Page >>

Save & Return Later

Fontan Systems of Care Inventory

Routine Fontan Surveillance - Invasive Testing

Please complete the following table, as it relates to invasive testing for individuals with Fontan circulation at your care center:

	Readily Available at Center:	Routinely/regularly recommended:	Recommended in most or all patients at some point:	If recommended, How often for standard Fontan surveillance:
Cardiac catheterization	☐	☐	☐	
Liver biopsy, transjugular	☐	☐	☐	
Liver biopsy, transcutaneous	☐	☐	☐	

Any other invasive testing routinely recommended?

- ○ Yes, describe:
- ○ No

reset

Q&A

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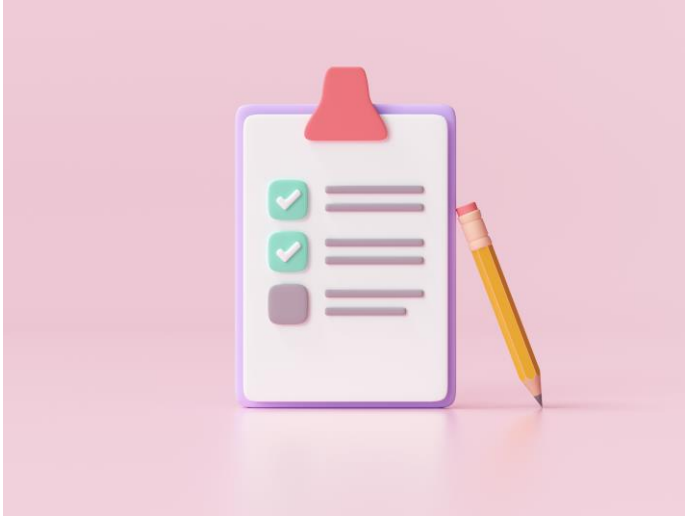
NPC-QIC FON Learning Community



Complete the Evaluation form to obtain CME/CNE credit

Help us improve future learning sessions by submitting feedback!

Evaluation link:

Spring 2024 FON NPC-QIC Virtual Learning Session Evaluation (cchmc.org)

Questions or issues?
Email info@npcqic.org or info@fontanoutcomesnetwork.org

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Fall Learning Session / Single Ventricle Patient Day
St. Louis
Save the Date!
OCTOBER 25 -26

Get Involved!

Attend FON quarterly **Care Center Forums.** These forums are open to Clinical Research Coordinators, people doing the data entry or overseeing/working with the registry (reach out to info@fontanoutcomesnetwork.org for details).

Identify **centers to connect** with post-Learning Session, using connections from your Team Time.

Keep an eye out for the **FON Physical Activity & Exercise grade school tools** on the FON website! They will be announced in an upcoming newsletter (fontanoutcomesnetwork.org).

Sign-up in early Summer for the **Physical Activity & Exercise Improvement Project** open to FON & NPC Center Teams

Attend **FON Case Review Conferences**. Open to all members; learn more about challenging cases from colleagues. (fontanoutcomesnetwork.org/events)

Questions? Reach out to info@fontanoutcomesnetwork.org or info@npcqic.org.

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Get Involved!

Invite a **patient or family member representative** to our Fall 2024 Learning Session (10/25-10/26 in St. Louis)

Invite **Spanish-speaking patients and families** to explore the FON & NPC-QIC websites once they are live (will be announced in an upcoming newsletter)

Plan a research proposal – FON is opening for **research proposals** Summer 2024

Share your **ideas for the Post Glenn to Fontan Surgery** at info@npcqic.org

Consider a **surgical coaching visit** for your center

Questions? Reach out to info@fontanoutcomesnetwork.org or info@npcqic.org.

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Arkansas Children's Hospital

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Batson Children's Hospital University of Mississippi Medical Center

Boston Children's Hospital

Children's Healthcare of Atlanta

Children's Hospital and Medical Center, Omaha

Children's Hospital Los Angeles (CHLA)

Children's Hospital of New Orleans (CHNOLA)

Children's Hospital of Philadelphia (CHOP)

Children's Hospital of Pittsburgh of UPMC

Children's Hospital of Wisconsin

Children's Hospitals and Clinics of Minnesota

Children's Medical Center Dallas

Children's Memorial Hermann Hospital

Children's Mercy Hospitals and Clinics Kansas City

Children's National Medical Center

CHOC - Children's Hospital of Orange County

Cincinnati Children's Hospital Medical Center | University of Kentucky

Cleveland Clinic Children's Hospital

Cohen Children's Medical Center Northwell Health

Cook Children's Medical Center

Dell Children's Medical Center, Texas Center for Pediatric and Congenital Heart Disease

Doernbecher Children's Hospital

Duke University Medical Center

Evelina London Children's Healthcare (Start-up)

Inova Children's Hospital

Johns Hopkins All Children's Hospital

Kravis Children's Hospital at Mount Sinai, New York

Le Bonheur Children's Hospital - Memphis

Levine Children's Hospital - Sanger Heart and Vascular Institute

Lucille S. Packard Children's Hospital, Stanford

Mattel Children's Hospital UCLA Pediatric Cardiology

Medical University of South Carolina

Monroe Carrell Jr Children's Hospital at Vanderbilt

Nationwide Children's Hospital

Nemours Cardiac Center, A.I DuPont Hospital for Children

Nemours Children's Hospital Orlando

New York Presbyterian - Morgan Stanley Children's Hospital

Nicklaus Children's Hospital

Norton Children's Hospital

NYU Medical Center

Ochsner Hospital for Children

Penn State Hershey Children's Hospital

Phoenix Children's Hospital

Primary Children's Medical Center | Intermountain Health

Rady Children's Hospital | UC San Diego Health

Riley Hospital for Children

Seattle Children's Hospital

SSM Health Cardinal Glennon Children's Hospital

St Louis Children's Hospital

Stollery Children's Hospital , University of Alberta

Sunrise Children's Hospital

Sutter Medical Center - Sacramento

Texas Children's Hospital

The Children's Hospital Colorado (CHCO)

The Children's Hospital of Montefiore

The Hospital for Sick Children

University Hospitals Case Medical Center - Rainbow Babies & Children's Hospital, Pediatric Heart Center

University of Florida , UFHealth

University of Maryland Children's Hospital

University of Rochester Medical Center

University of Texas Health Science Center, San Antonio (UTHSCSA) at University Hospital

UVA Children's Hospital

Thank you to our centers!

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Thank you to our Learning Session Planning Committee!

Kiona Allen, Cardiologist, FON QI Workgroup, Lurie Children's

Tammy Shepherd, Parent, Primary Children's

Tyler Sajdak, Individual w/Single Ventricle

Jo Ann Davis, Nurse Practitioner, SV Team, Nationwide Children's

Thank you to our NPC-QIC and FON Staff!

- Michelle Eversole, Project Manager
- Leann Stallard, Senior Specialist Project Management
- Rebecca Collins, Specialist, Project Management
- Sarah McGovern, Specialist, Project Management
- Kelly Diaspro, Coordinator, Program Management
- Shari Wooton, Lead Specialist Quality Improvement
- Adriana Ley Chavez, Specialist II Quality Improvement
- Mallory Moor, Specialist II Quality Improvement
- Jenne Slaw, Senior Specialist, Communications
- Dori Miller, Student Intern - Communications
- David Carlson, Senior Data Analyst
- Srujana Bandla, Data Analyst
- Jeff Theobald, Specialist, Data Management
- Emily Kuhnell, Lead Data Management
- Rohith Vanam, Senior Analyst, Business Intelligence
- Mark Timbers, Specialist, Regulatory Affairs
- Kenneth Mucheck, Clinical Research Coordinator
- Sarah Jones, Clinical Research Coordinator

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Welcome!

Selecting Improvers & Shining Stars – G-Charts & Funnel Plots

Will begin at 4:30pm ET

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Selecting Improvers & Shining Stars G-Charts & Funnel Plots

Mike Bingler MD (9:30 AM EST)/Lie Tjoeng MD (4:30 PM EST) Data Co-Leads

David Carlson MPH, Senior Data Analyst

Srujana Bandla B. Tech, Data Analyst

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Learning Objectives

- Develop an understanding of G-charts including:
  - How they differ from P-charts and Funnel plots
  - When and how they allow for earlier and/or real time identification of improvement
  - Potential shortcomings/limitations
- Describe how we selected which metrics to examine and how we identified improvers/shining stars
- Discuss how to interpret de-identified G-charts
- *Note: The main focus of this session is to learn additional QI methods rather than focusing on data and individual center improvement. Improvers and shining stars will be shared in the Learning Session intro.*

How did we get here?

- In Phase II, we have primarily used P-charts and Funnel plots to identify improvement and have been primarily looking at collaborative level data
- More recently, we have reached sufficient patient numbers (>3900) to evaluate and detect improvement at the individual center level
- We can now identify and celebrate individual centers who have excelled/shown improvement, focusing on data relevant to ongoing collaborative-wide improvement projects

What is a G-chart

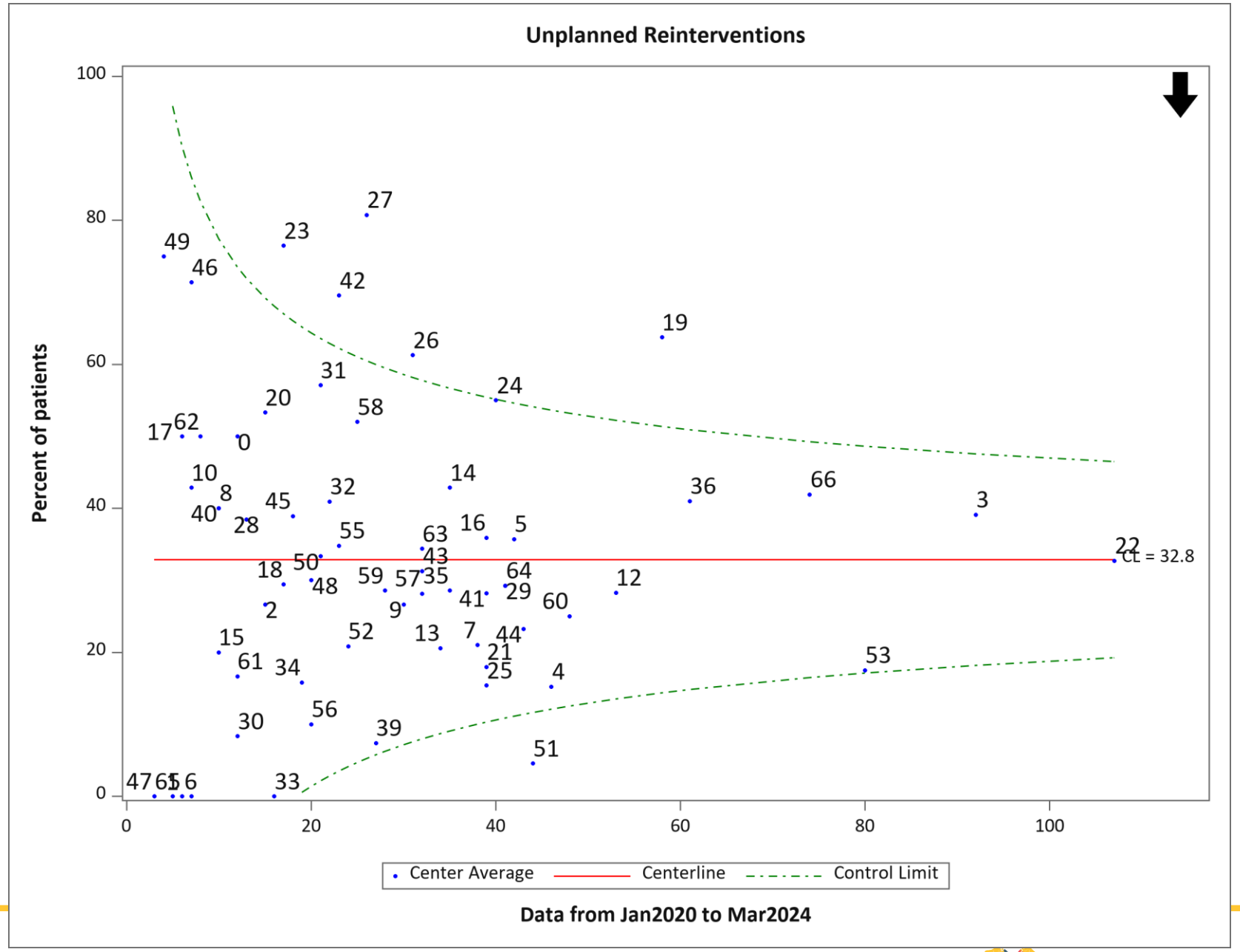
- A “geometric” chart is an alternative way to look at data when the incident of interest is relatively rare and some determination of opportunity (improvement) can be tracked
- Improvements are indicated by more patients reaching the desired outcome between patients experiencing the undesired outcome

Sensitive Material

The content that is about to be shared might be considered sensitive for some members of the community.

Please feel free to take a break or step away, if needed.

Funnel Plot

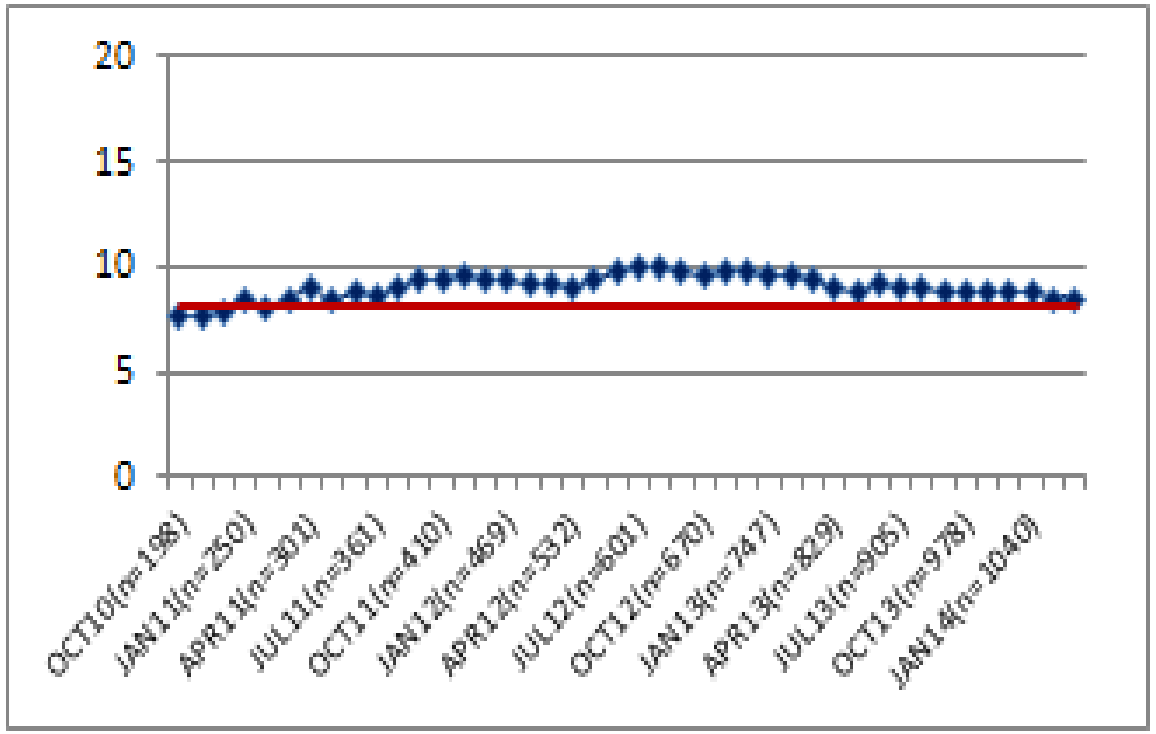

Unplanned Reinterventions
Percent of patients
100
80
60
40
20
0
0
20
40
60
80
100
CL = 32.8
Center Average
Centerline
Control Limit
Data from Jan2020 to Mar2024

Phase 1 mortality P-chart and G-chart

1. Mortality

Percent of patients who died out of

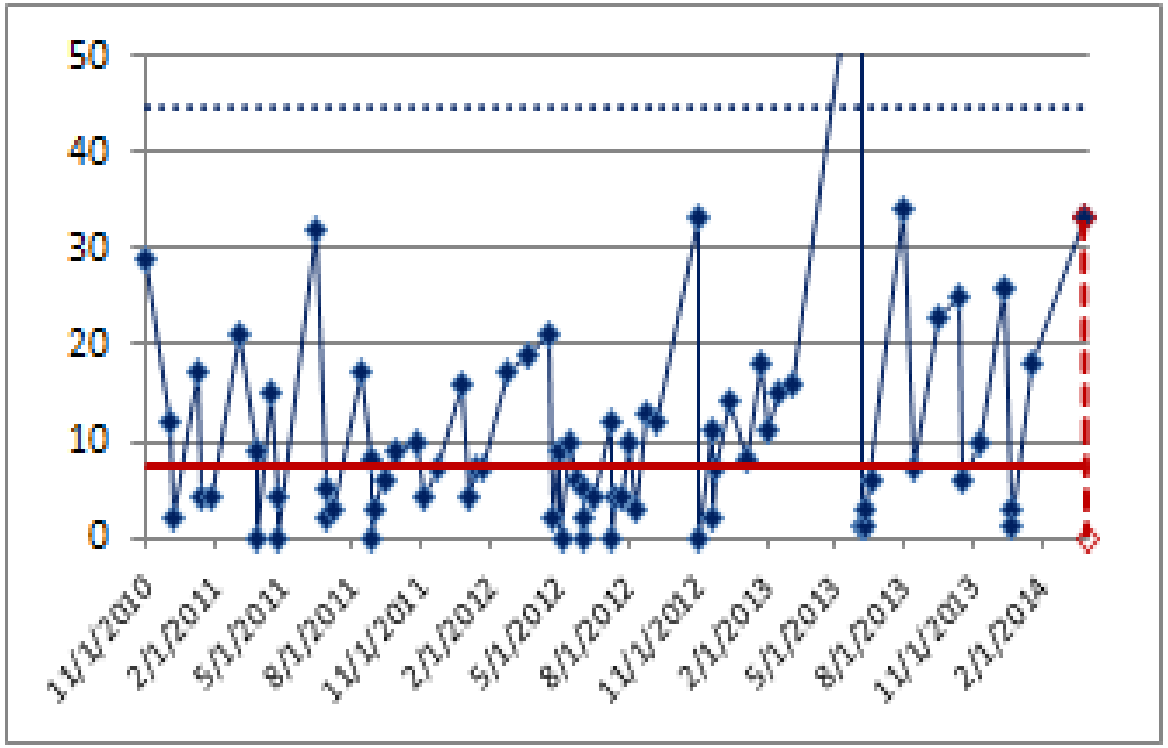
all patients who died, had a glenn or heart transplant



2. Mortality G-Chart

Number of patients who completed Glenn between each death.

Last point is no. of patients who completed Glenn since the last death.



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1. Mortality

Percent of patients who died out of

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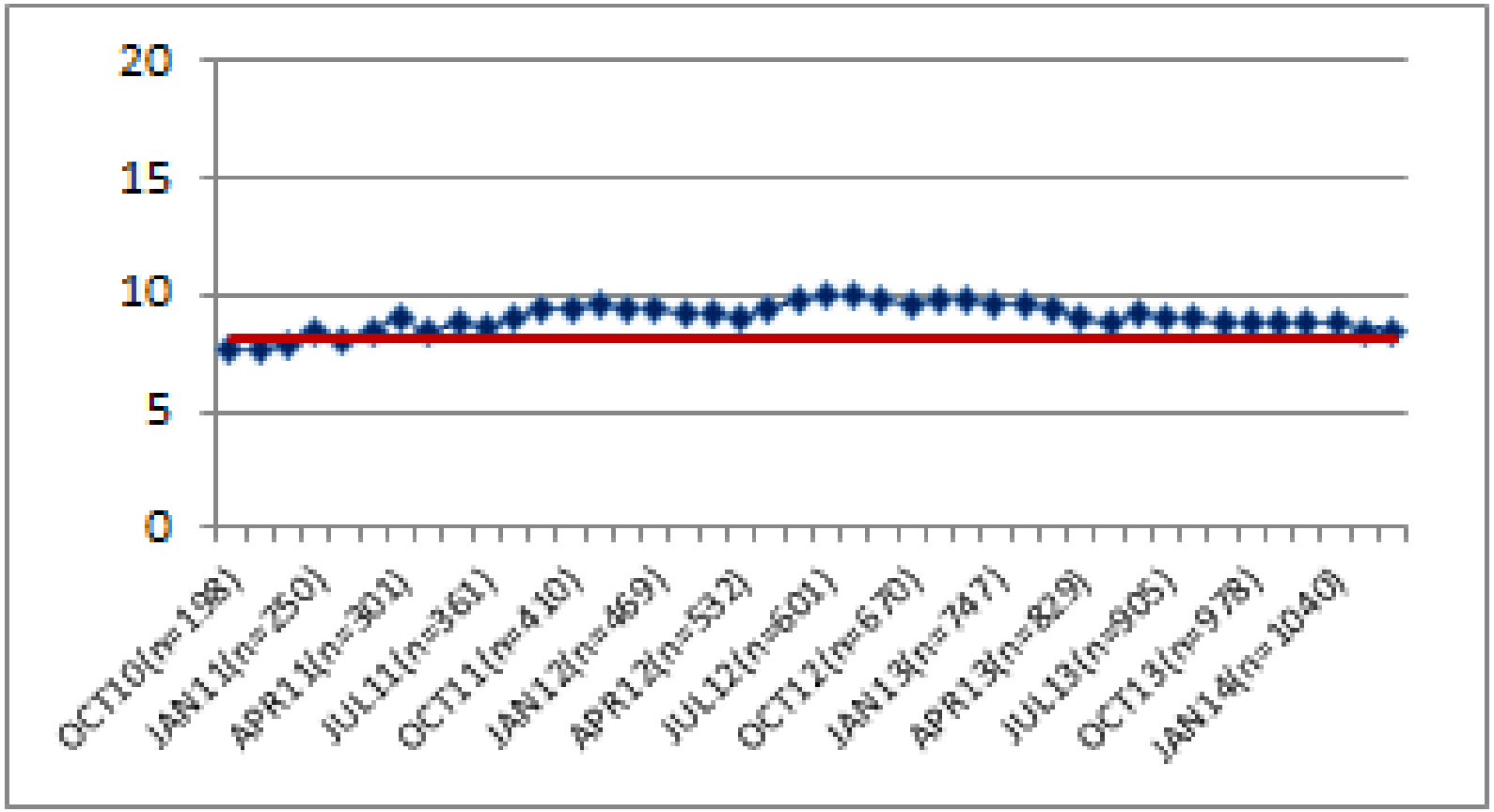

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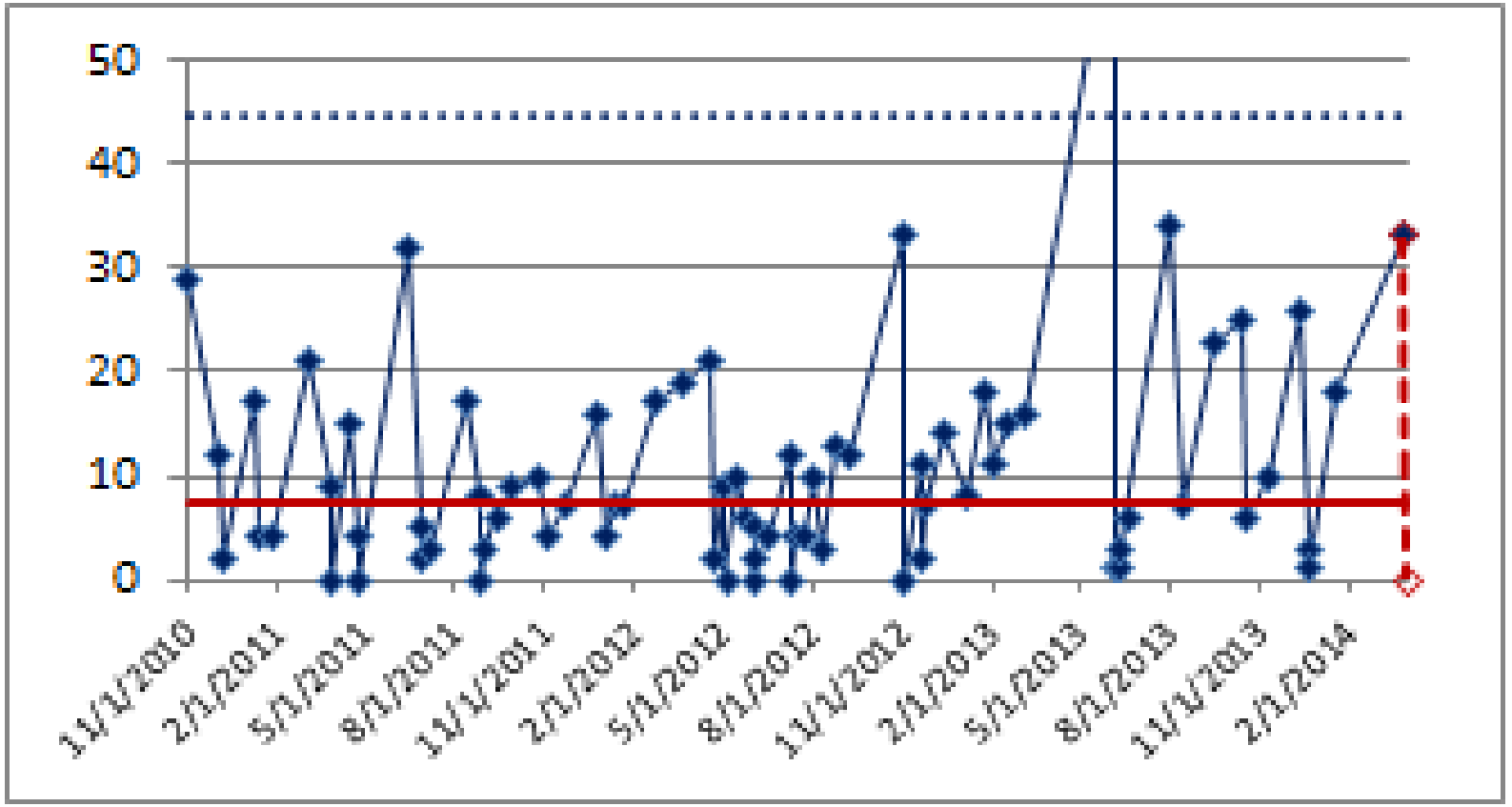

What is a G-chart?

Srujana Bandla, B. Tech

David Carlson, MPH

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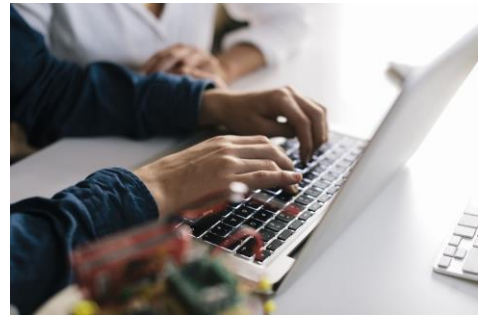
Polling Question

How comfortable are you with G charts?

1. No idea what's going on
2. Have seen them, but never used them
3. Basic understanding of the G chart
4. Can interpret most G charts with minimal assistance
5. Create my own G charts for fun on the weekends



G Chart - Introduction

- SPC Charts allow us to measure changes in our system; creating a centerline based on average values of data.
- Often these data are measured as percent of total events (P charts) or number of events per a denominator (U charts).
- When the standard attribute charts cannot be used due to rare events, a G-chart can be used in its place.

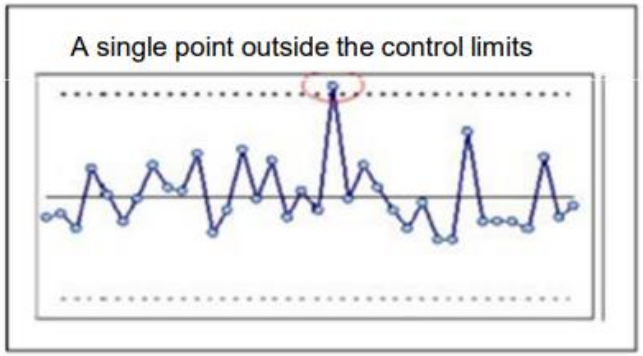
G Chart Advantages

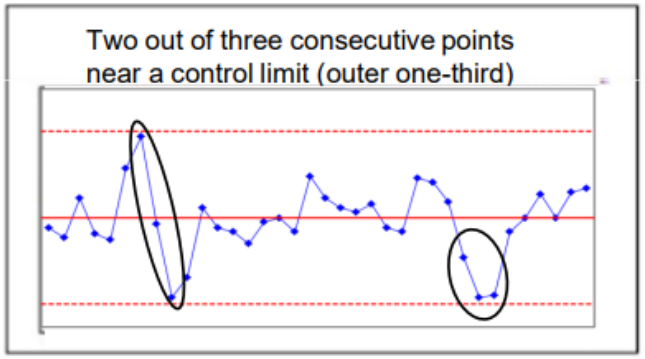
- Allows for measuring improvements in a quicker timeframe than with other attribute charts
  - Does not require bucketing data into months or other time blocks

- Removes the effect rare events can have on typical attribute SPC charts (i.e. sufficient sample size)
  - P charts require a certain number of events per month to calculate
  - For instance, measures that have centerlines at 10% would require at least 14 patients per month.
  - Rarer events would require an even larger number of patients per month.

Provost LP, Murray SK. The Health Care Data Guide – Learning From Data for Improvement. 2nd Ed. Hoboken, NJ: John Wiley & Sons, Inc.; 2022.

G Chart Disadvantages





Disadvantages:

- Difficulty in interpretation as many of the chart elements are modified from typical attribute charts
  - Why we are here today
- No LCL is available for measuring change
  - Other special cause rules can still be used
- Small numbers can still be an issue with collecting enough data to interpret

Template maintained by The James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center.

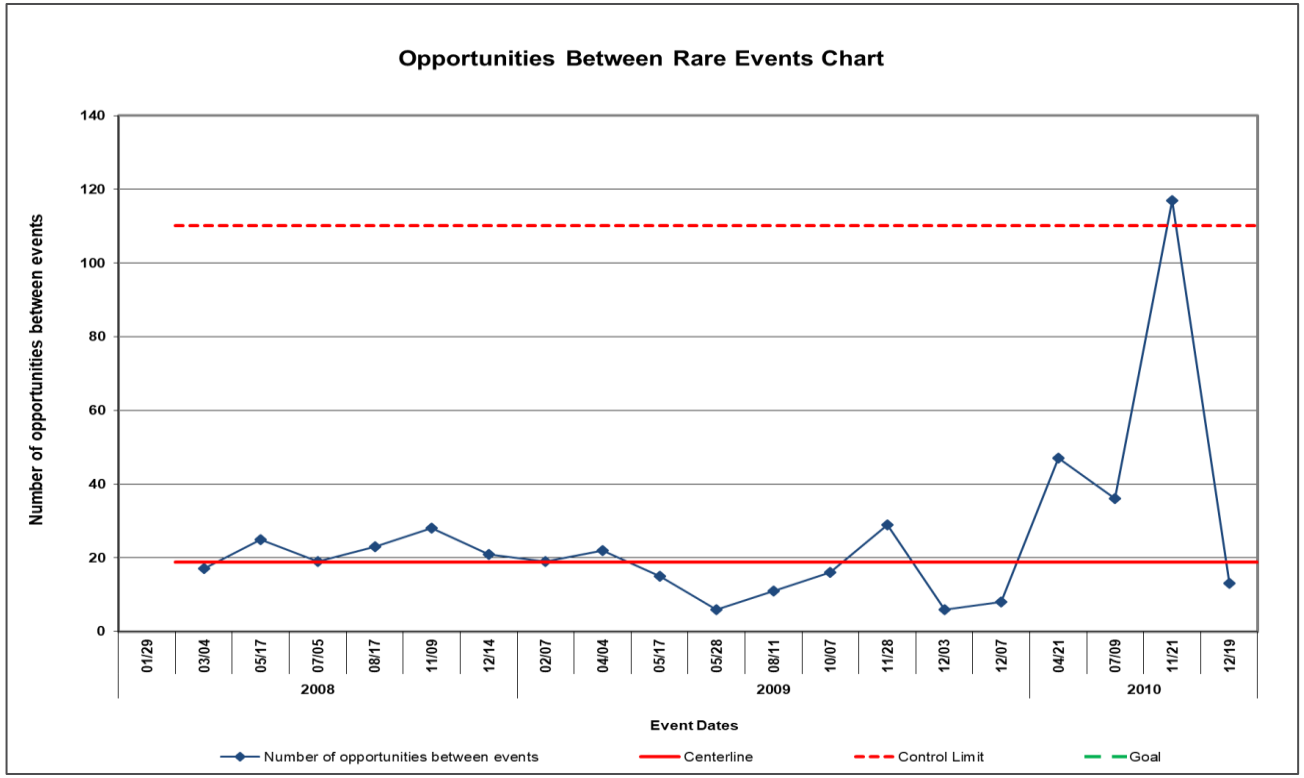
Organizing the data

- Data for C, U, and P charts are typically organized by various date buckets (i.e. # or rate of some outcomes per month).
- Data for G charts are aggregated by number of successful events between non-conforming events.
- In the table to the right, we can see how the data are calculated for both a C and G chart.

Data for C Chart		Data for G Chart	
Month	Number of Readmissions	Date of Readmission	Consecutive Admissions Since Last Readmission
1/1/2008	1	1/29/2008	
2/1/2008	0	3/4/2008	17
3/1/2008	1	5/17/2008	25
4/1/2008	0	7/5/2008	19
5/1/2008	1	8/17/2008	23
6/1/2008	0	11/9/2008	28
7/1/2008	1	12/14/2008	21
8/1/2008	1	2/7/2009	19
9/1/2008	0	4/4/2009	22
10/1/2008	0	5/17/2009	15
11/1/2008	1	5/28/2009	6
12/1/2008	1	8/11/2009	11
1/1/2009	0	10/7/2009	16
2/1/2009	1	11/28/2009	29
3/1/2009	0	12/3/2009	6
4/1/2009	1	12/7/2009	8
5/1/2009	2	4/21/2010	47
6/1/2009	0	7/9/2010	36
7/1/2009	0	11/21/2010	117
8/1/2009	1	12/19/2010	13

Anatomy of a G chart: What am I looking at?

- G charts use many of the same elements that are used on various SPC charts, they are just modified to represent that data differently:
  - Title and labels
  - X-axis
  - Y-axis
  - Plotted values
  - Upper control limit (UCL)
  - Centerline (CL)



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For those centers wanting more:

Below are the key elements and formulas used in creating G charts:

- Number of opportunities between = g
- Number of subgroups = k
- Average = $\bar{g} = \sum g/k$
- Centerline = 0.693 $\bar{g}$
- Upper Confidence Limit = $\bar{g} + 3\sqrt{\bar{g}(\bar{g} + 1)}$

Provost LP, Murray SK. The Health Care Data Guide – Learning From Data for Improvement. 2nd Ed. Hoboken, NJ: John Wiley & Sons, Inc.; 2022.

Selection Criteria

- During the Learning Session, a list of improvers and shining stars will be shared.

- These centers were chosen using the following criteria:
  - **Shining stars** – Outside the funnel plot in a favorable direction for the measure from January 2020 through February 2024
  - **Improvers** – a point above the upper control limit (UCL) in G chart measure during January 2022 – February 2024

Understanding G charts:
Interactive Exercises

Srujana Bandla, B. Tech

David Carlson, MPH

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Dipping our toes in….together

Date of Patient's first birthday	100% Oral feeds at 1st birthday
6/27/2017	Success
7/28/2017	Failure
9/22/2017	Success
10/11/2017	Success
11/29/2017	Failure
2/18/2018	Failure
3/11/2018	Failure
7/10/2018	Failure
7/13/2018	Failure
10/2/2018	Success
1/23/2019	Failure
3/13/2019	Success
5/25/2019	Success
5/29/2019	Success
6/3/2019	Failure

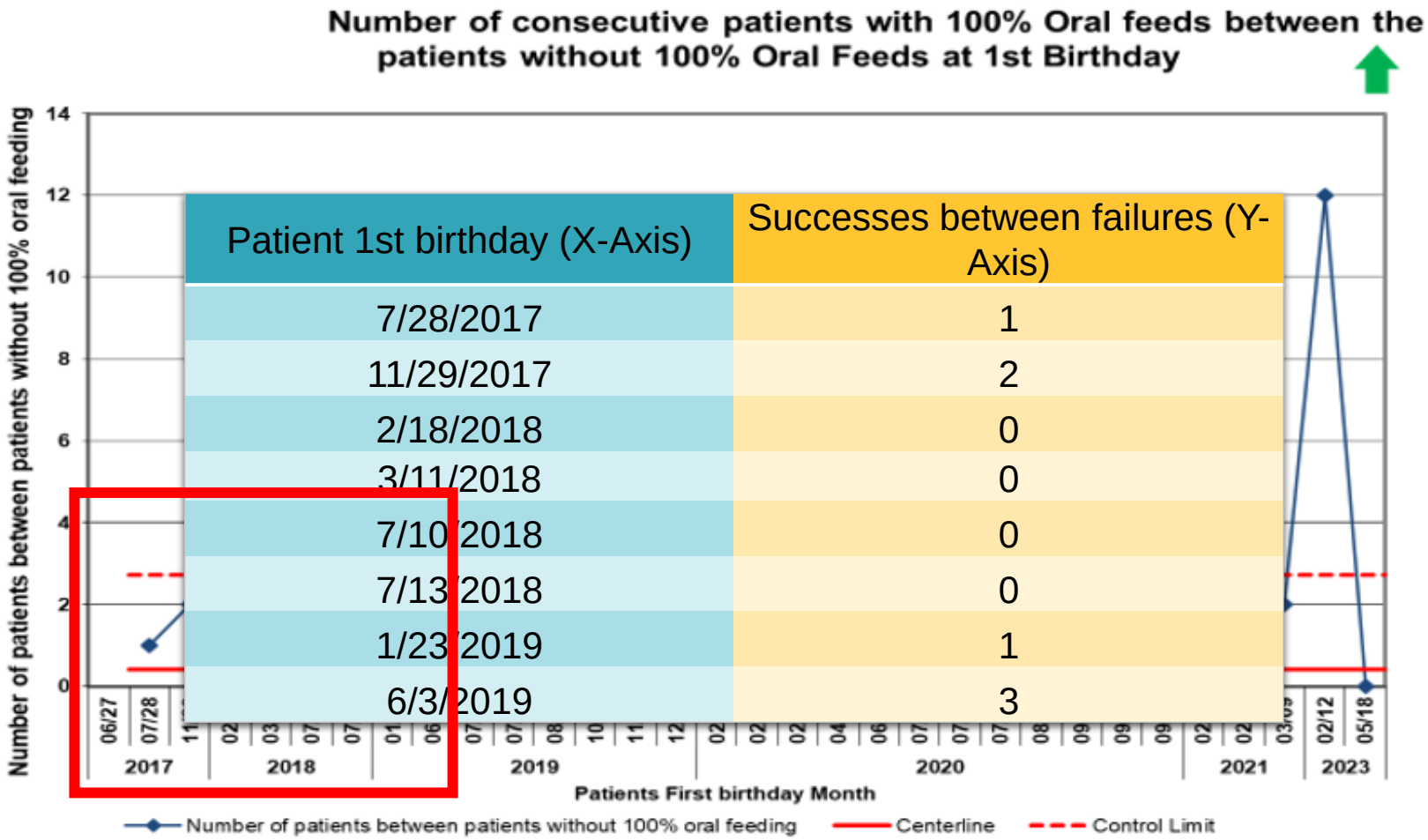
Sort for Failures →

X-axis ↓

Y-axis ↓

Date of Patient's first birthday	100% Oral feeds at 1st birthday	Successes between failures
7/28/2017	Failure	1
11/29/2017	Failure	2
2/18/2018	Failure	0
3/11/2018	Failure	0
7/10/2018	Failure	0
7/13/2018	Failure	0
1/23/2019	Failure	1
6/3/2019	Failure	3

Dipping our toes in….together



Patient 1st birthday (X-Axis)	Successes between failures (Y-Axis)
7/28/2017	1
11/29/2017	2
2/18/2018	0
3/11/2018	0
7/10/2018	0
7/13/2018	0
1/23/2019	1
6/3/2019	3

National Pediatric Cardiology Quality Improvement Collaborative

FONTAN OUTCOMES NETWORK

Show us what you can do

Date of Stage 1 Surgery	Prenatal Support
1/18/2020	Yes
3/2/2020	No
3/29/2020	No
4/1/2020	Yes
5/19/2020	Yes
6/4/2020	No
6/29/2020	No
7/11/2020	Yes
8/3/2020	No
9/23/2020	Yes
9/31/2020	Yes
10/27/2020	No
11/3/2020	No
11/31/2020	Yes
12/22/2020	No

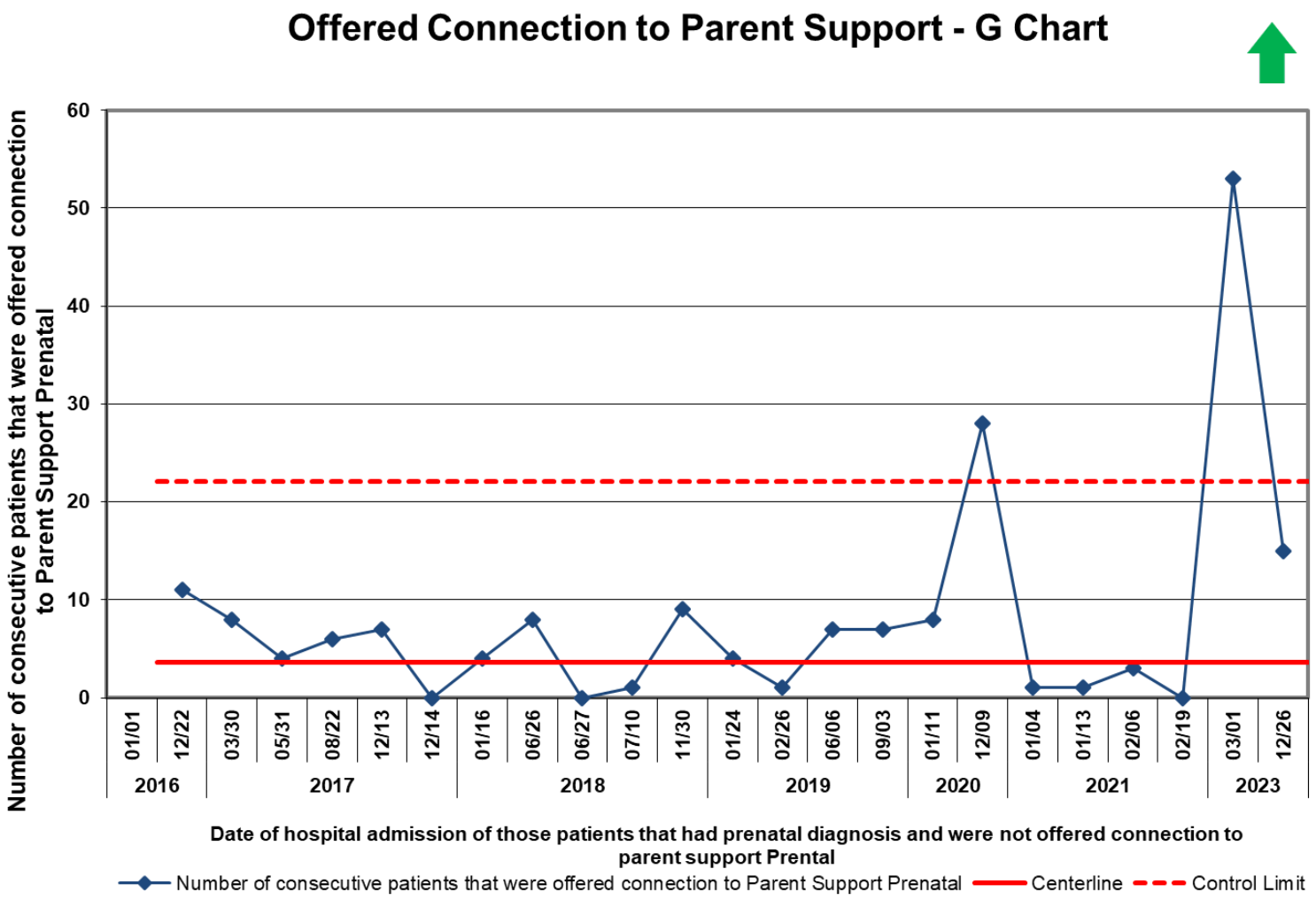
Sort for Failures →

Date of Admission	Successes between
3/2/2020	1
3/29/2020	0
6/4/2020	2
6/29/2020	0
8/3/2020	1
10/27/2020	2
11/3/2020	0
12/22/2020	1

Questions for consideration:

- *What are considered the non-conforming events?*

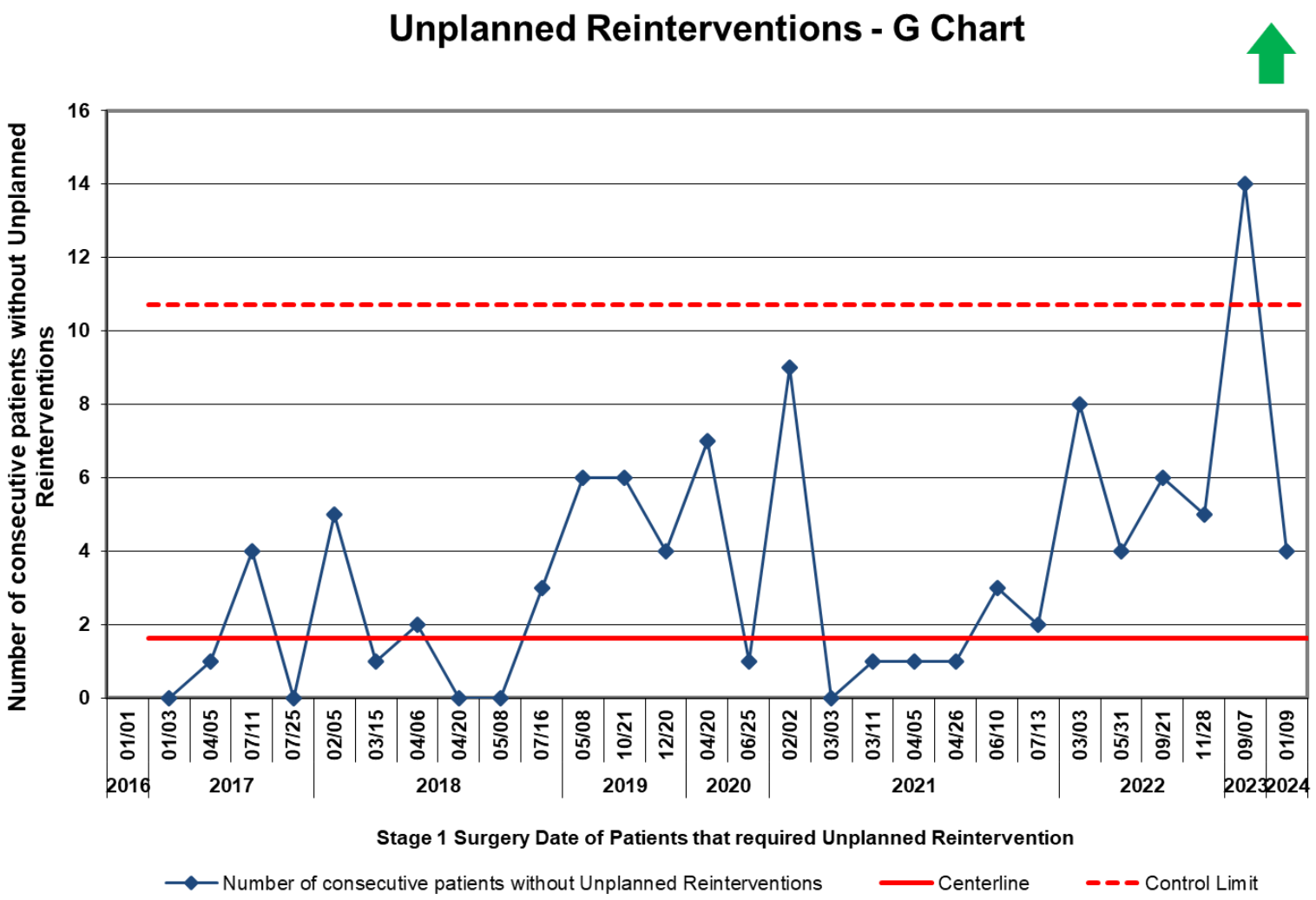
Show us what you can do



Questions for consideration:

- *Where would you look first on this G chart? Why?*

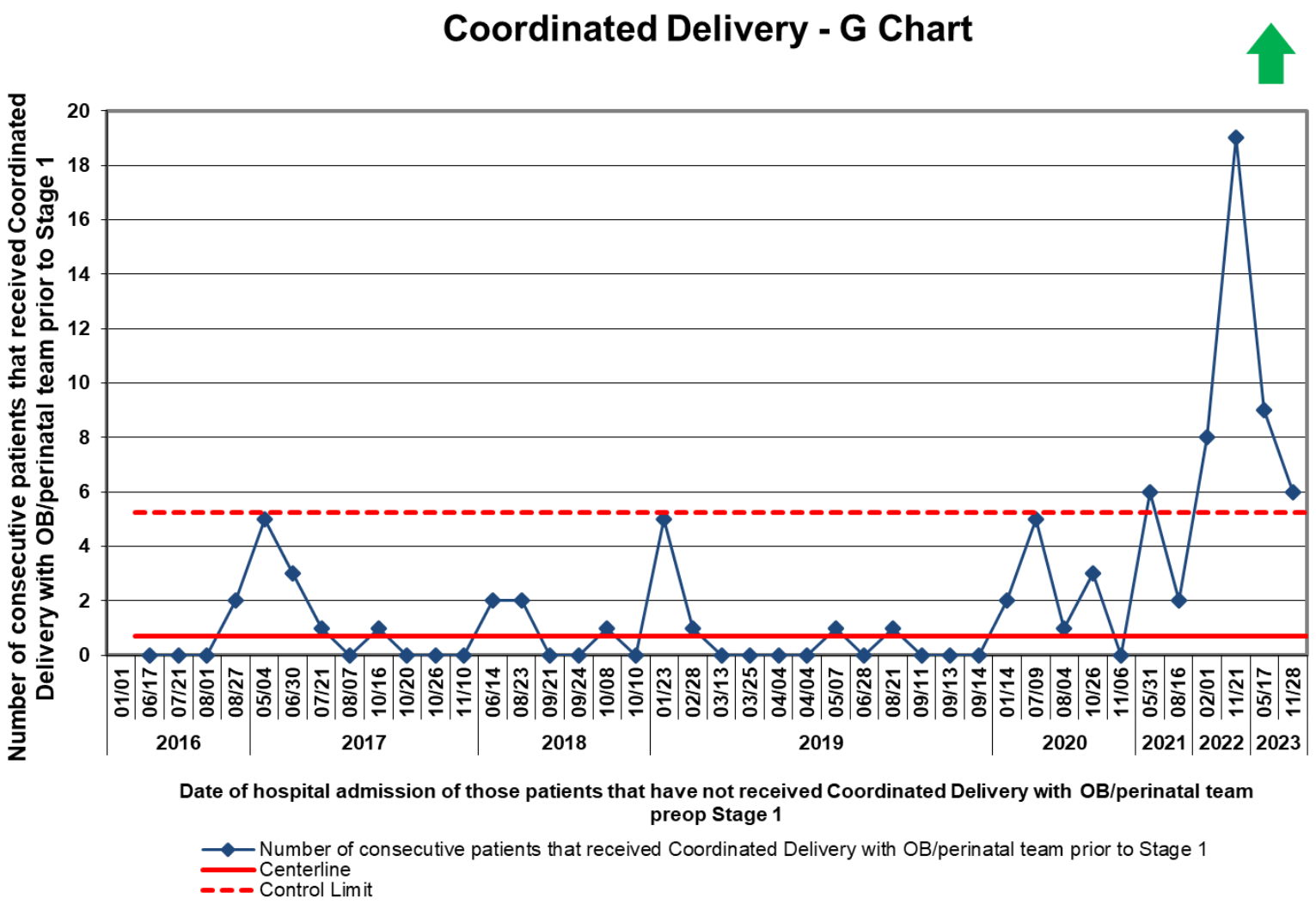
Show us what you can do



Questions for consideration:

- *What does the centerline represent?*

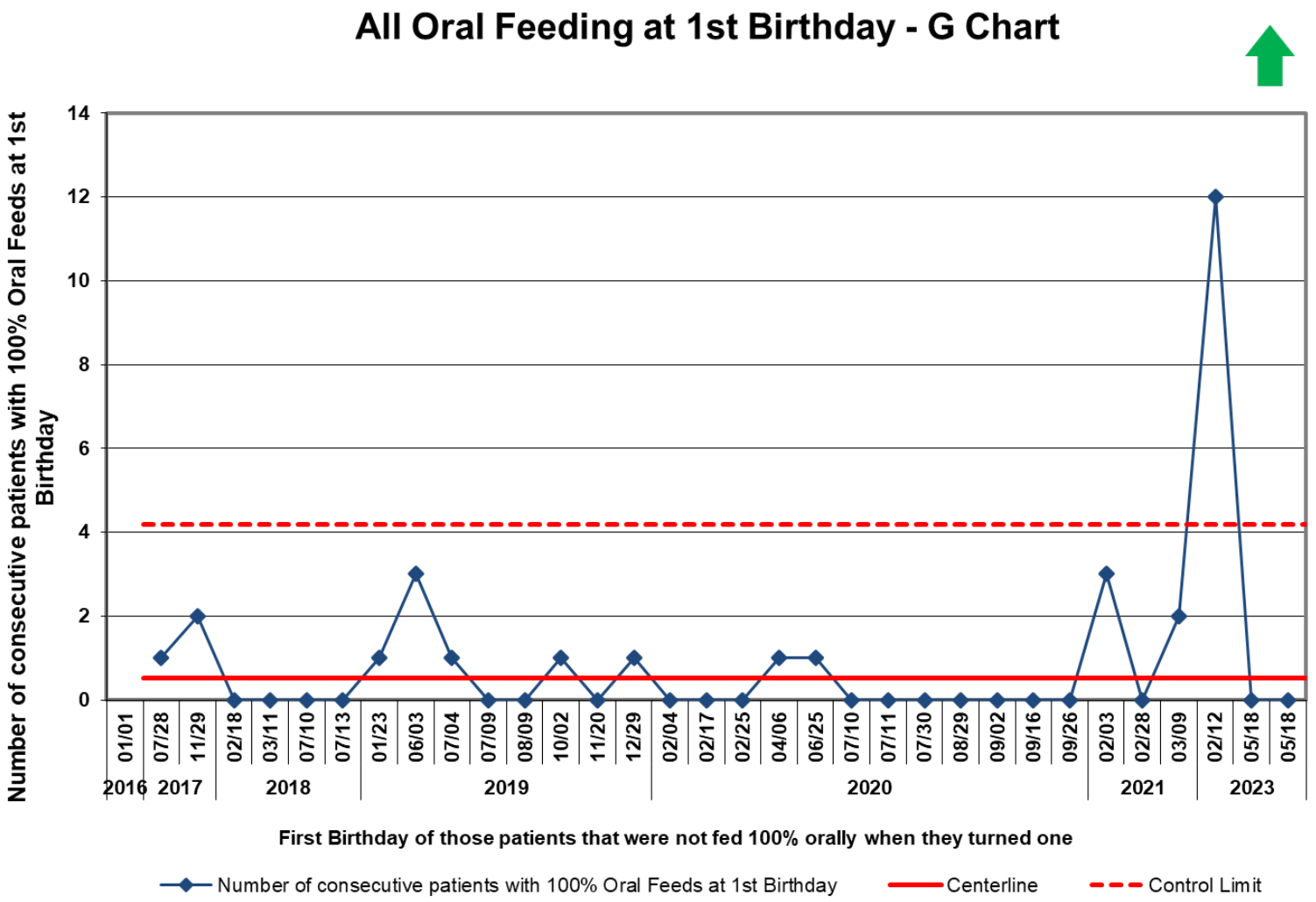
Show us what you can do



Questions for consideration:

- *How would explain what this chart is showing?*

Show us what you can do



Questions for consideration:

- *How would you summarize what the chart is telling us?*

Next Steps

- Continue to look at center level G-charts to identify improvers in other areas
- Continue to celebrate those centers that show improvement
- Potentially create a list of centers that have improved in certain areas to allow other centers to reach out to improvers for thoughts on how they achieved success

Questions?

Thank You for Joining Us Today!

National Pediatric Cardiology
Quality Improvement Collaborative

FONTAN
OUTCOMES NETWORK