### CARDIOLOGY 2024

Pediatric QI Work as a Model for the Fontan Outcomes Network:

What Can We Learn from Other Networks? What are the Possibilities for Single Ventricle Care?

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#### **Learning Health Networks**



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National Pediatric Cardiology Quality Improvement Collaborative

> ASH RESEARCH

COLLABORATIVE"

Accelerating Progress





**IMPROVECARENOW** 





PAC

ADVANCED CARDIAC THERAPIES IMPROVING OUTCOMES NETWORK





#### Children's Hospitals' Solutions for Patient Safety Every patient, Every day.

Hall children







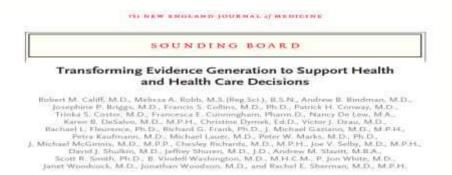
## WHAT IS A LEARNING HEALTH NETWORK?

Multisite community of patients, families, clinicians, and researchers who work together and *use data to improve outcomes, facilitate discovery, and spark innovation* 

### CENTRAL HYPOTHESIS OF A LEARNING HEALTH SYSTEM

By eliminating the boundaries between clinical care, research and improvement, and engaging everyone (patients, families, clinicians, researchers) as part of <u>one</u> system.....

## .....we will produce better outcomes and experience for patients and families, faster research, and lower costs



## **A LEARNING NETWORK IS:**

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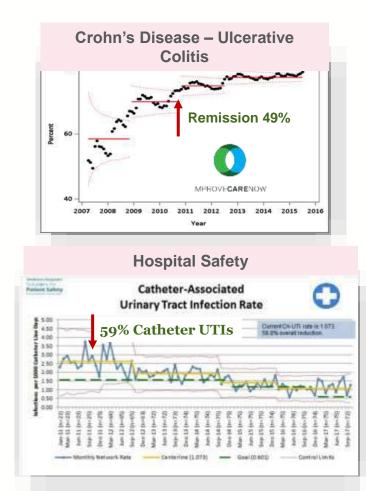


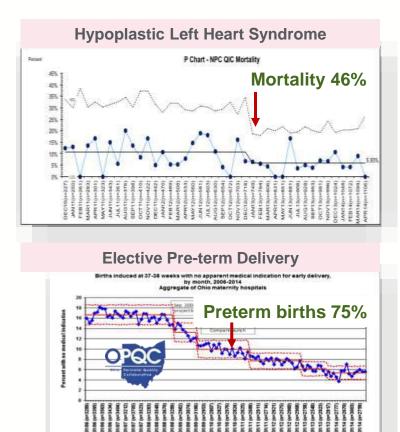
**3-part engaged social network:** patients, clinicians and researchers

Integrated **data-sharing** & technology

**Support for QI and research:** continuous improvement and learning

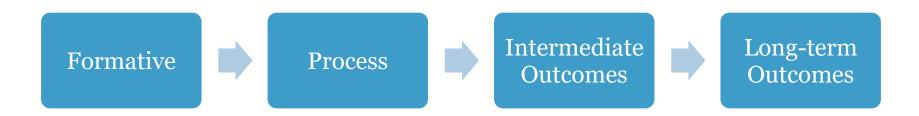
### The Learning Network Model Works In Various Settings



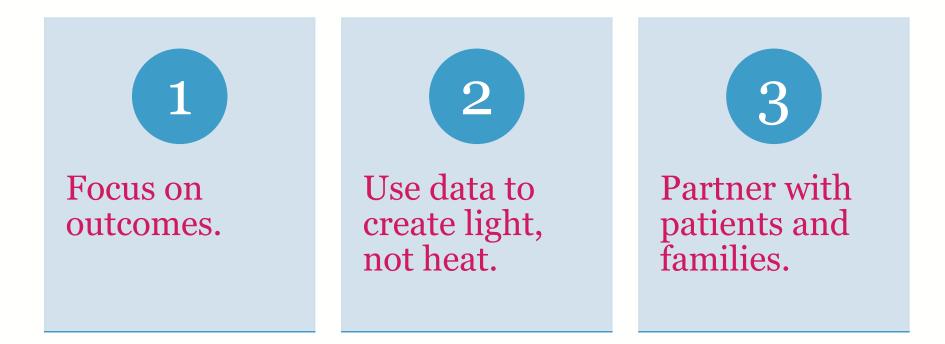


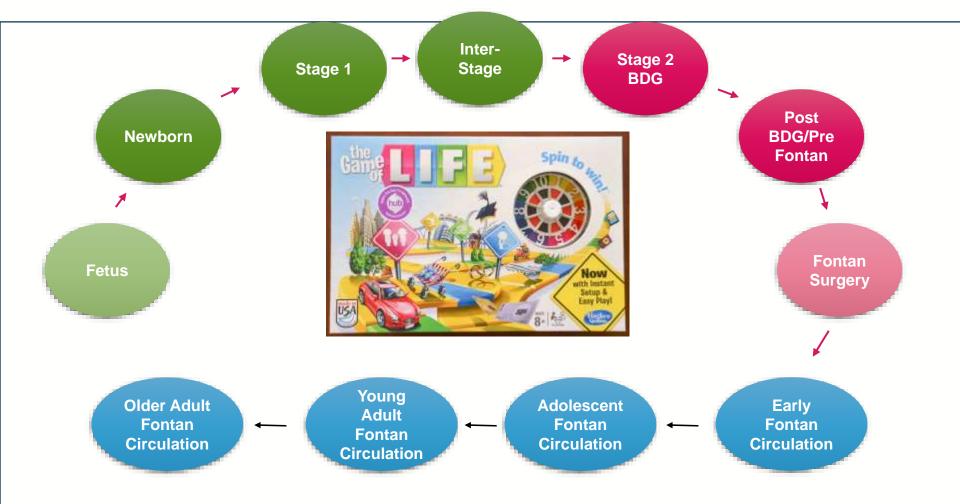
Jource: Ohio Department of Health, Vital Statistics

## **IMPLEMENTATION FRAMEWORK**



## **LESSONS LEARNED**





## FONTAN OUTCOMES NETWORK

To improve outcomes and quality of life for all individuals with single ventricle heart disease and Fontan Circulation

Optimize longevity and quality of life by dramatically improving:

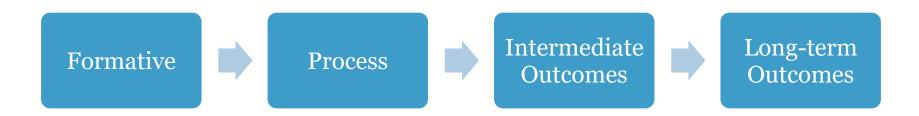
- Physical health & functioning
- Neurodevelopment
- Emotional health & resilience

## FONTAN OUTCOMES NETWORK

Will merge with NPC-QIC to become One Lifespan Single Ventricle Network

(name TBD!)

## **IMPLEMENTATION FRAMEWORK**



## **STRATEGIES TO IMPROVE THE SYSTEM**

- •Standardize processes
- •Use shared decision-making
- •Learn from one another in network
- •Test changes using QI methods

## **REMEMBER HIGH SCHOOL CHEMISTRY CLASS?**

moles of solute

solution

Making a known molar solution: Molarity (M) =

top off to 1 liter MoGraw

## DEFINITION OF *RELIABILITY* FOR HEALTH CARE

The capability of a process, procedure or health service to perform its intended function in the required time under existing conditions.

## **DEFINITIONS OF RELIABILITY**

*Chaotic process*: Failure in greater than 20% of opportunities

Level 1: (10<sup>-1</sup>) 80-90 percent Reliability. (1-2 failures out of 10 opportunities)
Level 2: (10<sup>-2</sup>) Approx 95% Reliability. (<5 failures out of 100 opportunities)</li>
Level 3: (10<sup>-3</sup>) Approx 99% Reliability. (<5 failures out of 1000 opportunities)</li>

## **RELIABILITY & EVIDENCE BASED CARE IN HEALTH CARE SETTINGS**

## Observation:

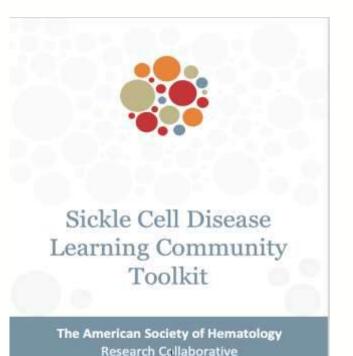
Almost all studies that investigate the reliability of the application of clinical evidence conclude that most would be classified as a Chaotic process or a 10<sup>-1</sup> process.

## AN EXAMPLE OF USING THE FRAMEWORK

### SICKLE CELL DISEASE LEARNING COMMUNITY

### Aim: Improve the Reliable Use of

- Disease-Modifying Therapies
- Co-Developed Pain Management Plans



September 2022

## **UNDERSTANDING YOUR SYSTEM**

#### Formative

- Systems Inventory (what do teams think is happening?)
- Process Map (draw the process you think is happening; is it ideal?)

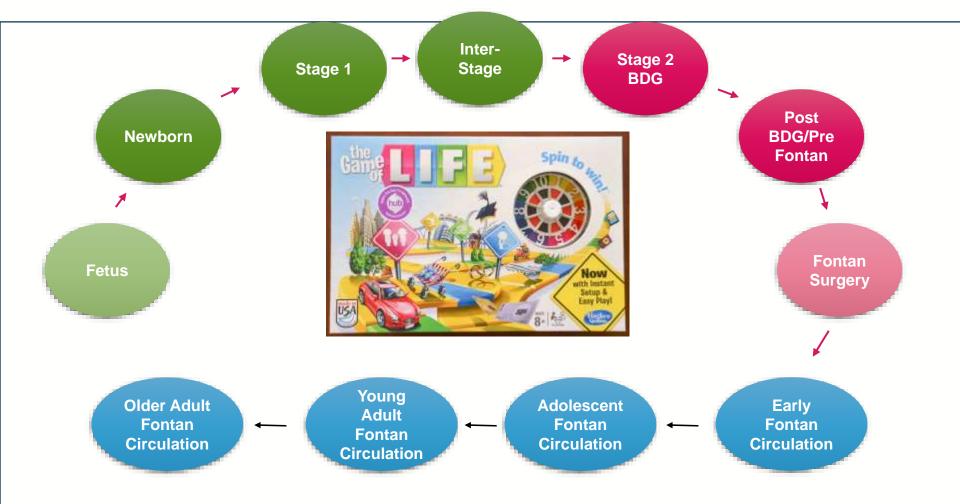
#### Process Data

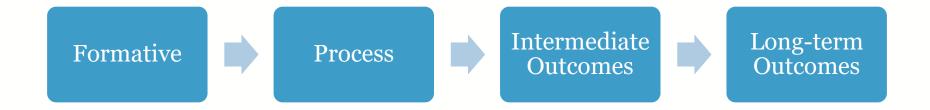
- Reliability Sampling (what do our charts tell us is *really* happening?)
- Patient Report/Assessment: (what do the patients say is happening?)
- Outcome Data (both intermediate and long-term)
  - Data (% patients with Rx for medication → pain crises, hospitalizations, longevity)

## FONTAN OUTCOMES NETWORK

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## FONTAN OUTCOMES NETWORK

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Optimize longevity and quality of life by dramatically improving:

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- Emotional health & resilience









Transplant



Birth Control, Pregnancy, Family Planning FON community of care centers and patients identified 5 themes



## **PHYSICAL ACTIVITY/EXERCISE**



## **TOOLKIT DEVELOPED** PLANNING FOR LAUNCH OF A QI PROJECT IN 2024



**Analytics** 

-

FONTAN

#### **Development Of A Toolkit For Active Living With Fontan Circulation:** A Fontan Outcomes Network Quality Improvement Initiative

Janua Harasan, MD, Michael Dandsten, MR, Casary Yugal, 1991, Janeil Harabarann, MD, Borl Janeilann, MD, Mangan Huang, Phonie Proster: Livette Wyler, EXN, INJ, CPN, Andrew Holemann Matthack WHI, Ralama, Nalam, MIW, Andreys Dolds, CMN, Carella Jancow, MD, Mithi en Indely With Protocol Occurrence Networks,

#### BACKGROUND

- Revises citualization has been historically defined by programing database to sectors capacity and health related quality of the (Calc)
- These functional limitations are associated with poor health outcomes
- Buddethere on physical activity (IA) are still common Evidence that PA can be sets and may be beneficial for those with Fortan.
- ownedation unitances to grow
- Members of the Foltan Outcome tertwalk (FOM), a multisenser learning health. network of patients, families, and thermost, designed a Webooked improvement project that whic to imprive subclines through physically active Ithophyles for all individuals and families with Fontan constations.

- RESULTS
- \* We designed the toolkit to have physical activity as an activity of daily living + Active play at home is promoted through developmentally appropriate mator skill progressions
- Patients and families are guided through building partnerships with schools and community programs to
- support active thotake · Contract threader are addressed, including task to improve everyor test countailing and management of
- esertainful symptoms + Gample quantums to help patients initials or engage in discussions about 76 with their care team are provided





A ..... Figure 2. Specific discovered, from our Build for future (Long with Figure Councilian of accounted laws. July again descentions of elevatively and expressed types arrived at executing planets and providences for the contacts and persons of the Contact Mathematication of Territor del proprezione se deporte se fruitabante to incrueg introduce to participate in activa communities, Right parel demonstration status to potents mits straggs with differentiating the terms alteratings, adaptitions to searche ficto patienting, companies

4-

#### CONCLUSIONS

- Supporting rate and active illective interpretations for individuals with Fontan provation is a top priority. for PON members
- · Our heat and is to test the feasibility and acceptability of tookst in real world use at member centers
- · rules studies examining the effects of the Mervestori or physical kinetioning, self-efficacy, and Dot. are planned

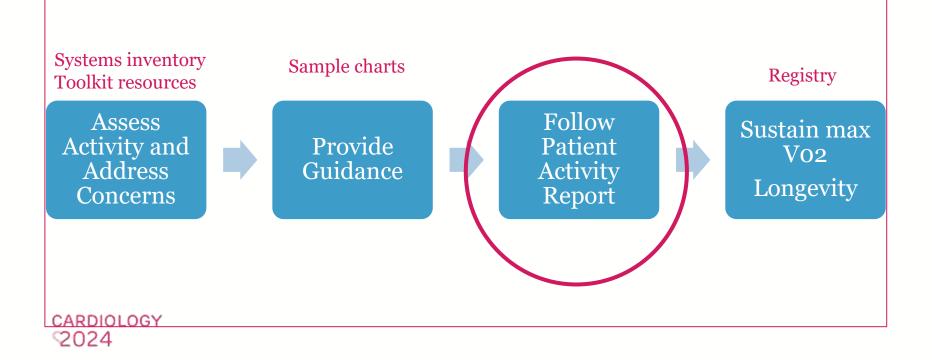
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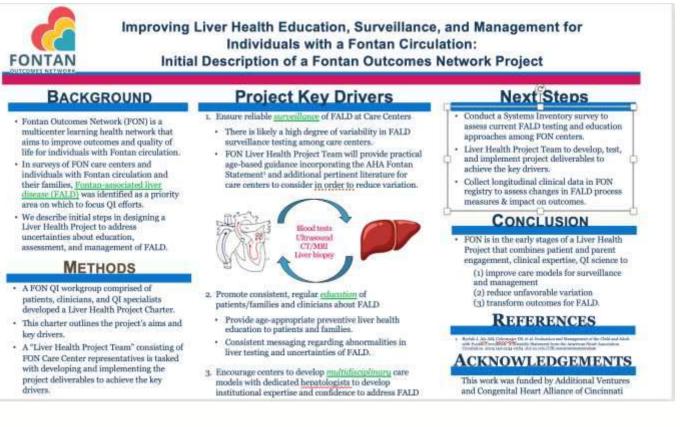
## FOCUS ON <u>RELIABLY</u> ADDRESSING PHYSICAL ACTIVITY--FOLLOW *INTERMEDIATE* OUTCOMES



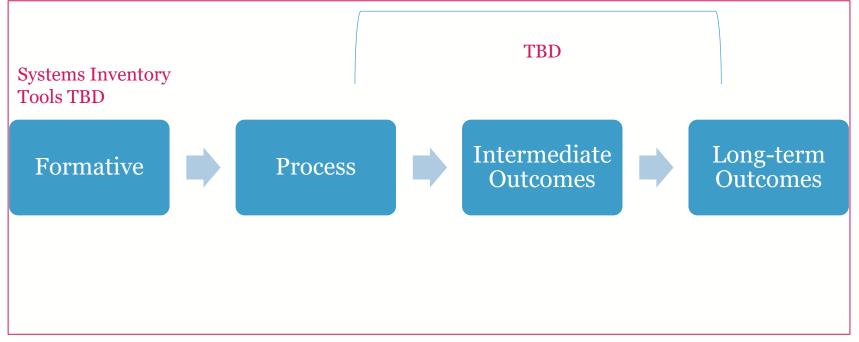
## **LIVER HEALTH**



## **IN DESIGN**



### FOCUS ON RELIABLY ADDRESSING LIVER HEALTH





## **EMOTIONAL HEALTH**

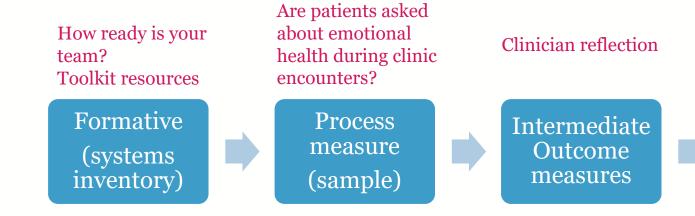






Aim: Patients living with chronic conditions and their families receive proactive support to promote emotional health as a routine part of excellent and equitable care.

## **ROADMAP ABP MOC COHORT**

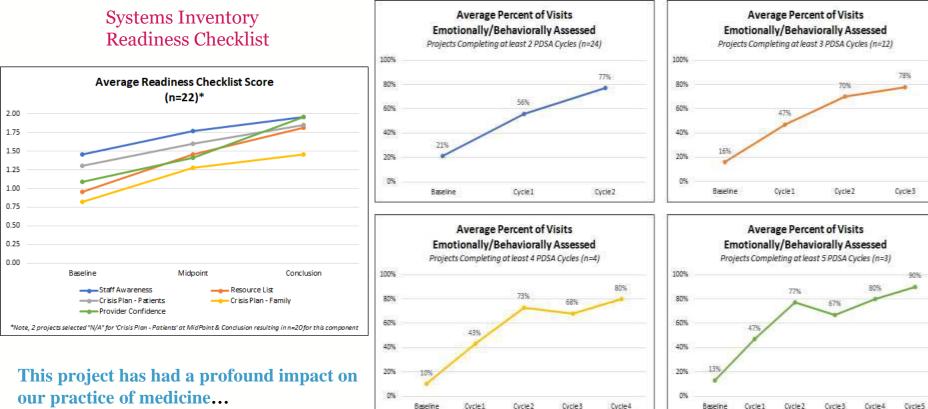


Long-term Outcome measures



### **Roadmap MOC cohort**

#### Process Measures (Sample of charts)



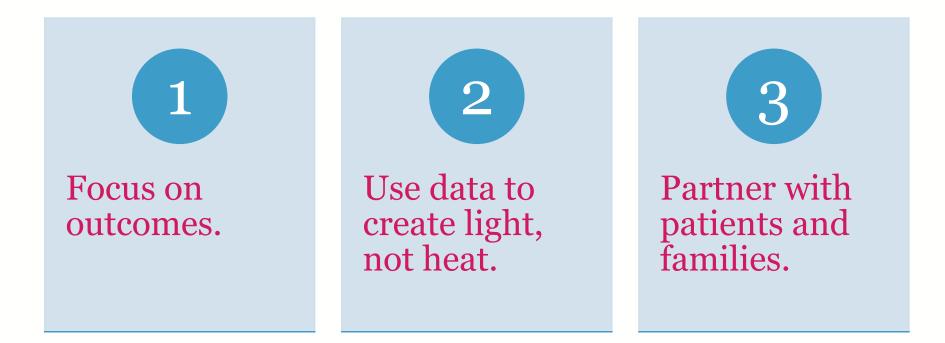
brought emotional health to the forefront

### CARDIOLOGY 2024

Pediatric QI Work as a Model for the Fontan Outcomes Network:

What Can We Learn from Other **Networks**? What are the Possibilities for Single Ventricle Care? The possibilities are endless and awesome!

## **LESSONS LEARNED**



### **LEVEL OF RELIABILITY**

### Level 1 (10<sup>-1</sup>)

#### Level 2 (10<sup>-2</sup>)

Level 3 (10<sup>-3</sup>)

### **COMPONENTS**

Standardization, Vigilance Awareness, Feedback

Decision Aids, Redundancy Desired Action is Default Real Time Identification of Failure, Checklists

Mindfulness Standardization of Behavior System is Visible