



HEALTHIER  
TOGETHER

**Compelling Vision**

**Proven Methods**

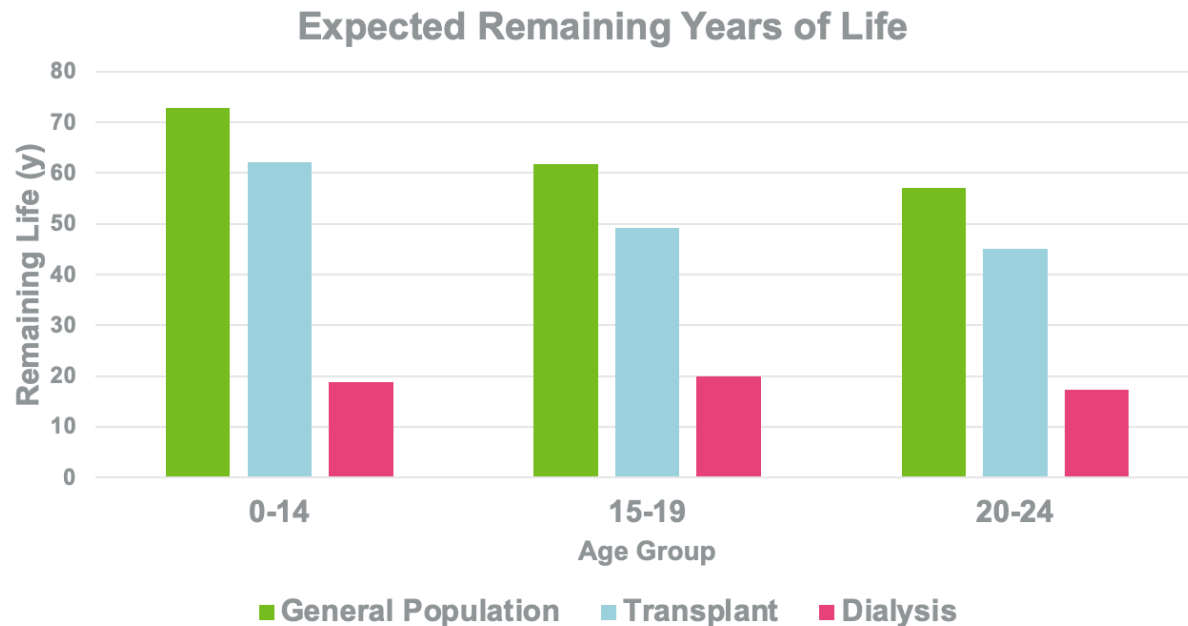
**Barriers to Scale**

# Agenda

- Brief Background
  - Compelling Vision:
    - A Story: What Get's in Your Way?
    - What is a Learning Health Network? How does it work?
  - Proven Methods
    - Success and Impact of Healthier Together Learning Networks
  - Barriers to Scale
    - Challenges to function, progress, and scale
    - Opportunities to realize vision
-

# Background

# People with ESKD die young



United States Renal Data System. 2020 USRDS Annual Data Report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020.

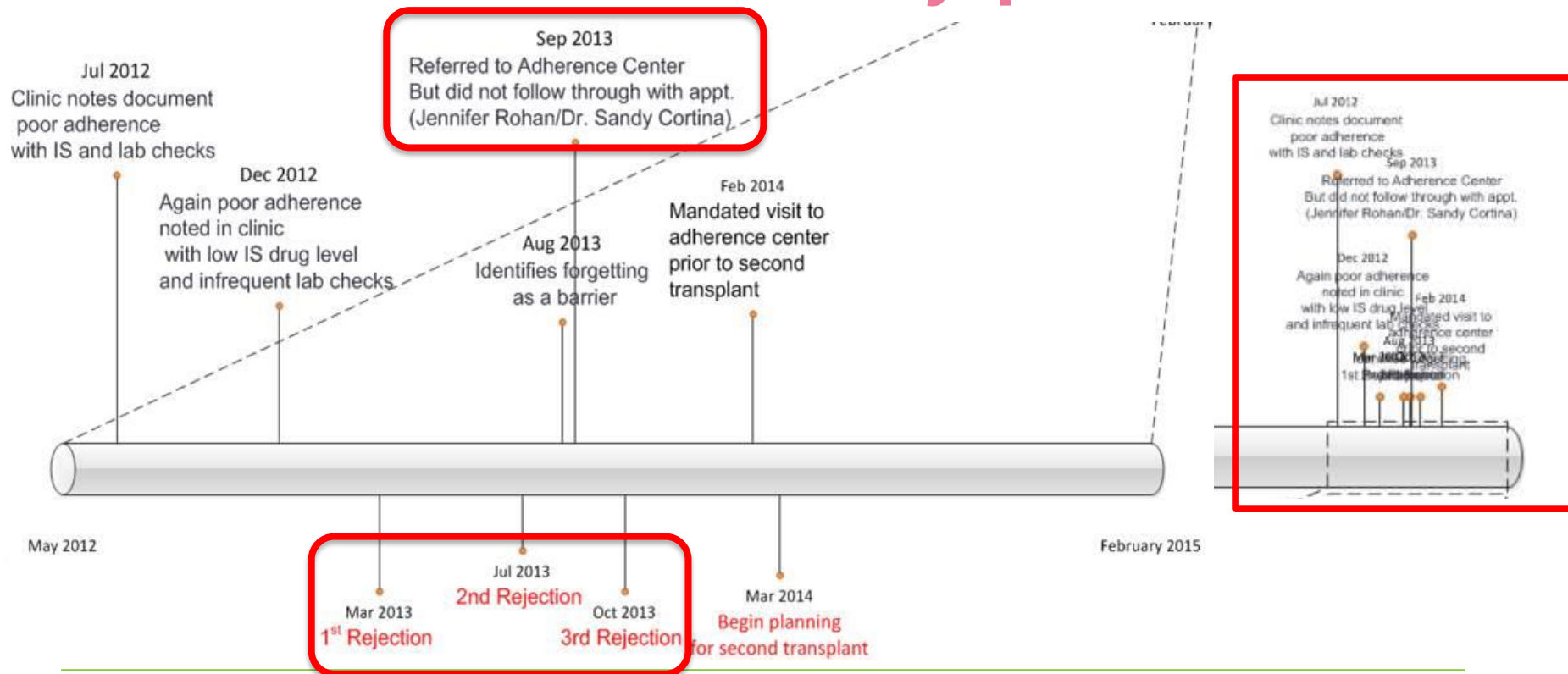
# Healthcare delivery system inadequate to address complex challenges

- Available therapies improve health, but they are not used reliably
    - Providers prescribe appropriate therapy < 60% of time
    - Patients experience barriers to taking their medication
      - poor adherence costs \$300 billion annually in the US
    - 40% of kidney transplant failure attributed to poor adherence
      - Return to dialysis costs the patient 35 years of life for care that costs 2-3 times as much
  - Rare conditions require multi-center collaboration to generate knowledge and know how
    - What to do...
    - How to get it done in actual practice
  - Translation of evidence into practice takes 17 years.
-

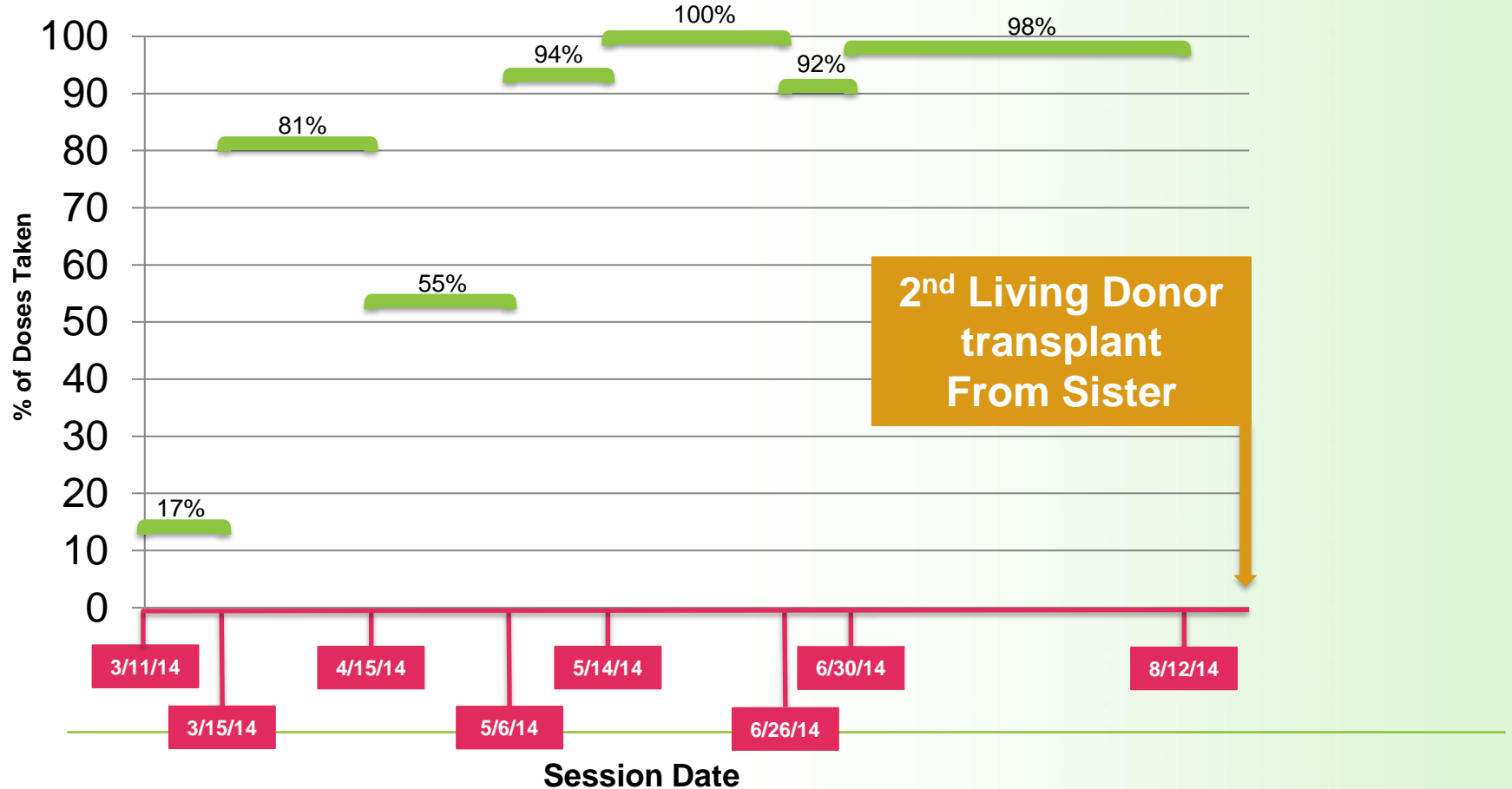
# Compelling Vision

A Patient Story

# Patient Born with Renal Dysplasia: KB



# Adherence Center: % of Doses Taken



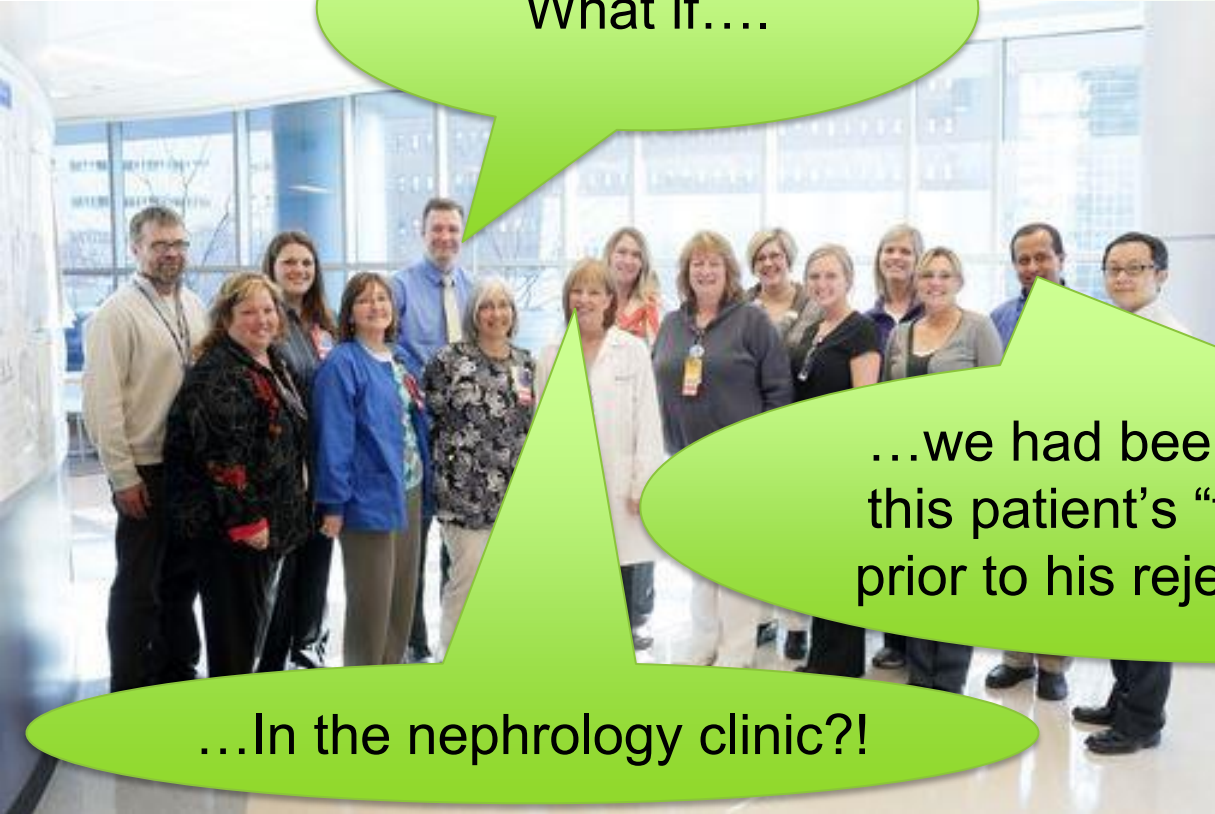


# Kidney Transplant Innovation Team

What if....

...we had been able to address this patient's "forgetting" barrier prior to his rejection episodes....

...In the nephrology clinic?!



# Co-production

patients, clinicians, researchers, administrators working together

# Patients, Clinicians, Researchers, Administrators



# Improving Renal Outcomes Collaborative



**Vision:** Partner with patients to improve health, longevity, and quality of life by engaging all stakeholders

# IROC INTERVENTION PACKAGES

PARTNERING TO ACHIEVE HEALTH, LONGEVITY, AND QUALITY OF LIFE



# IROC INTERVENTION PACKAGES

PARTNERING TO ACHIEVE HEALTH, LONGEVITY, AND QUALITY OF LIFE

## INTERVENTIONS BY PACKAGE

**REDUCE ACUTE ALLOGRAFT  
REJECTION**

**Kidney.Me**

Pre-Visit Planning

Customized Type & Group Visits

Transition Support

Caregiver's Virtual Roadmap

Individualizable Adherence Evaluation & Treatment Toolkit

**Improving Adherence**

Network-activated Peer Mentoring

Total Adherence App

Patient/Parent Exchange Platform

Transplant Pharmacist on Call

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Pre-Visit Planning with Adherence Data

**Rejection Prevention**

Central IRBs

**Research**

Explore Pediatrics vs Adult

Enhanced Solution Shop

IROC Exchange

Mentorship for Research

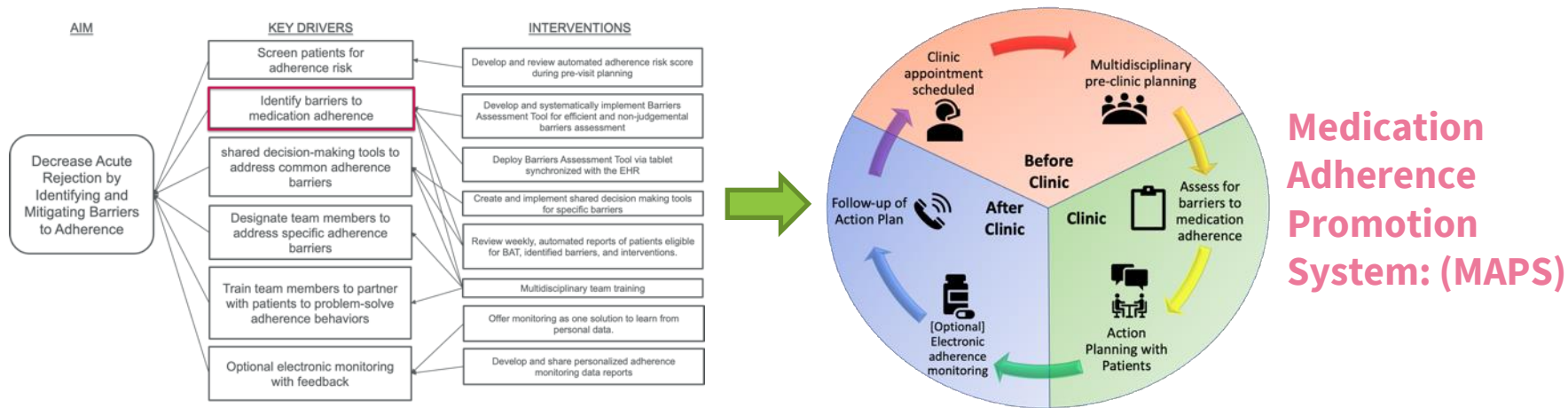
# Model for Improvement

Designing, testing, refining, implementing a Medication Adherence  
Promotion System at Cincinnati Children's Hospital

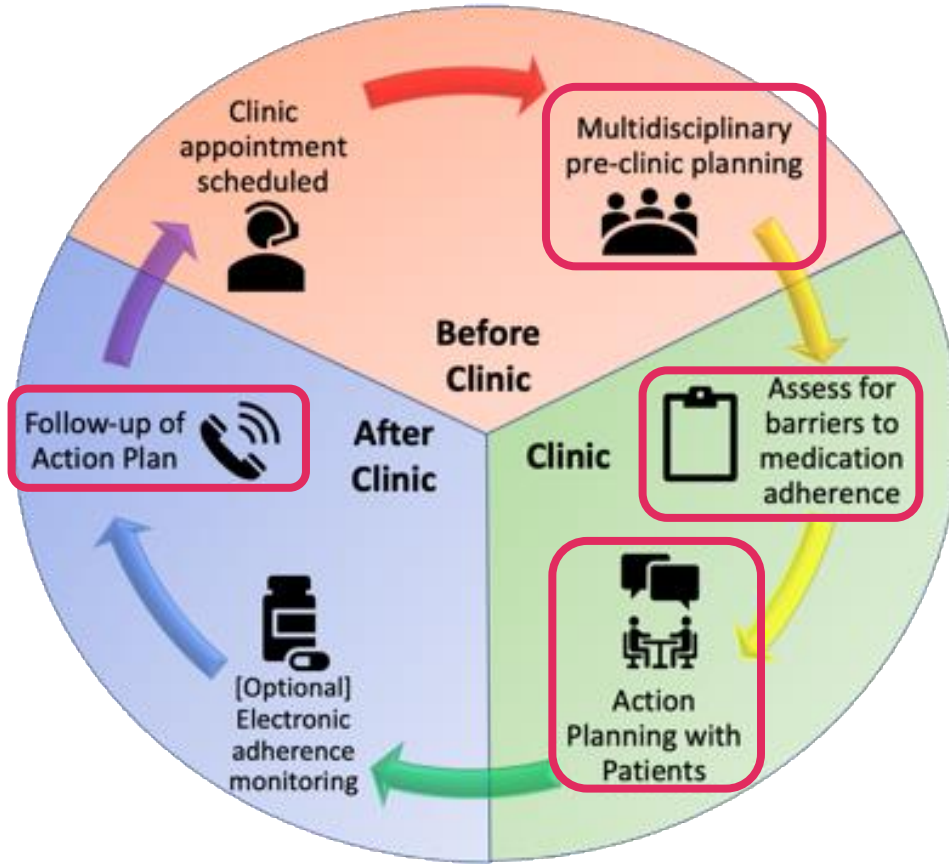


# Quality Improvement Project Aim

- Decrease late acute allograft rejection by:
  - Developing and implementing systems to identify and mitigate patient-identified barriers to adherence *in clinic* with *existing staff*







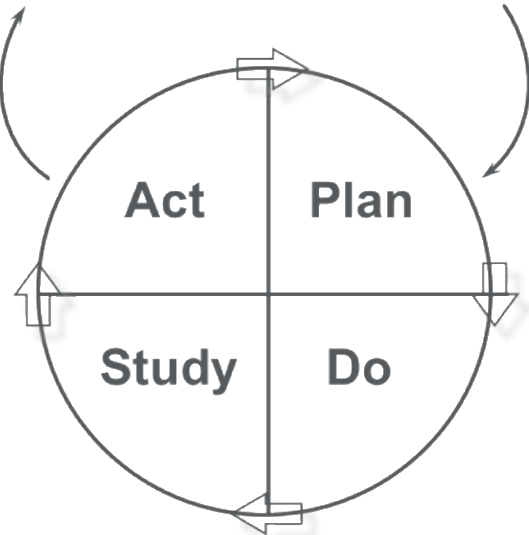
# Medication Adherence Promotion System: (MAPS)

## Model for Improvement

What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?



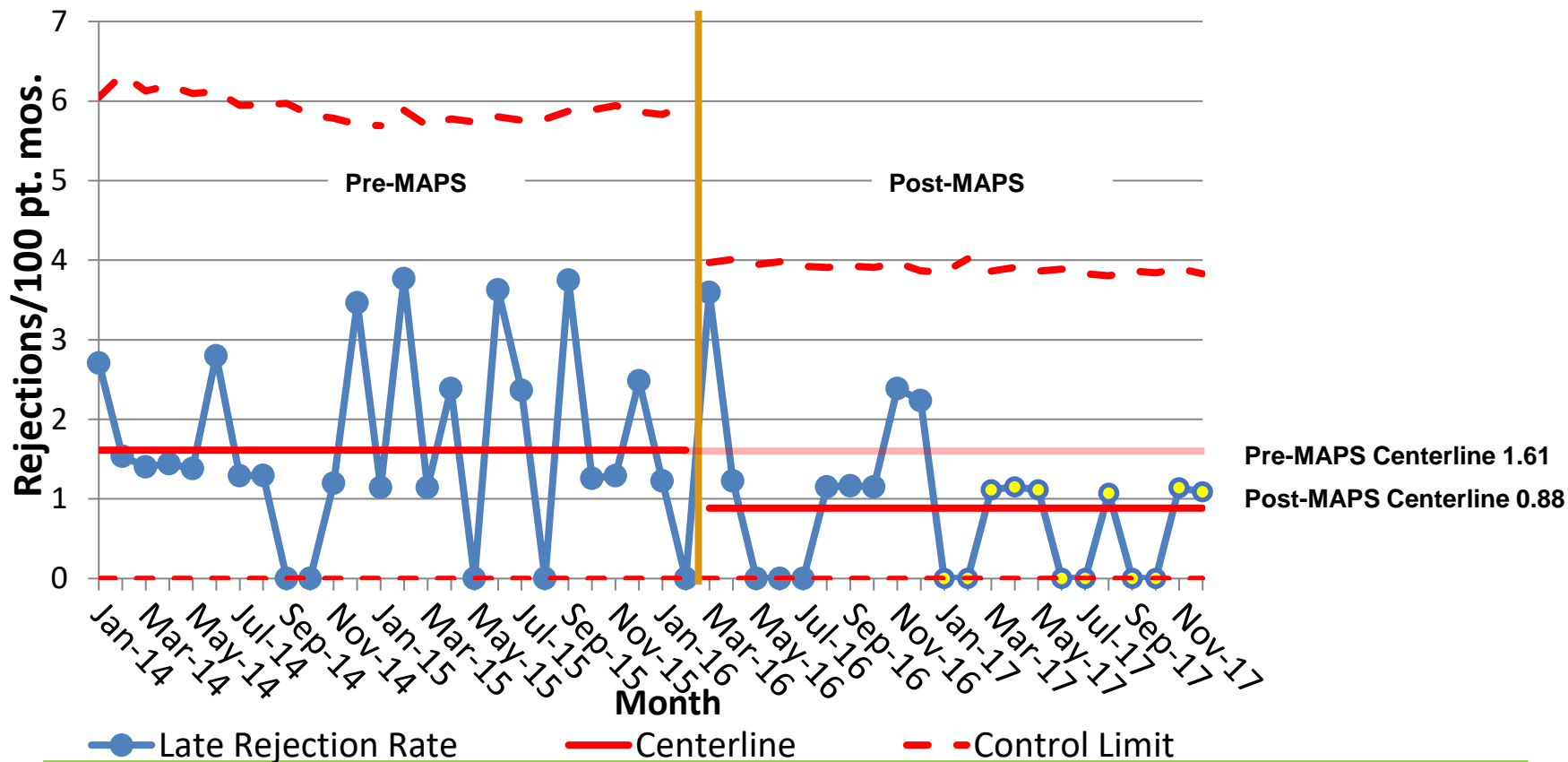
## Barriers assessment

Developed and refined through iterative testing with patients, parents, and providers.

- 14 item checklist (yes/no)

Reliably implemented through iterative testing through PDSA cycles starting with 1 patient, then 5, then 25, then all.

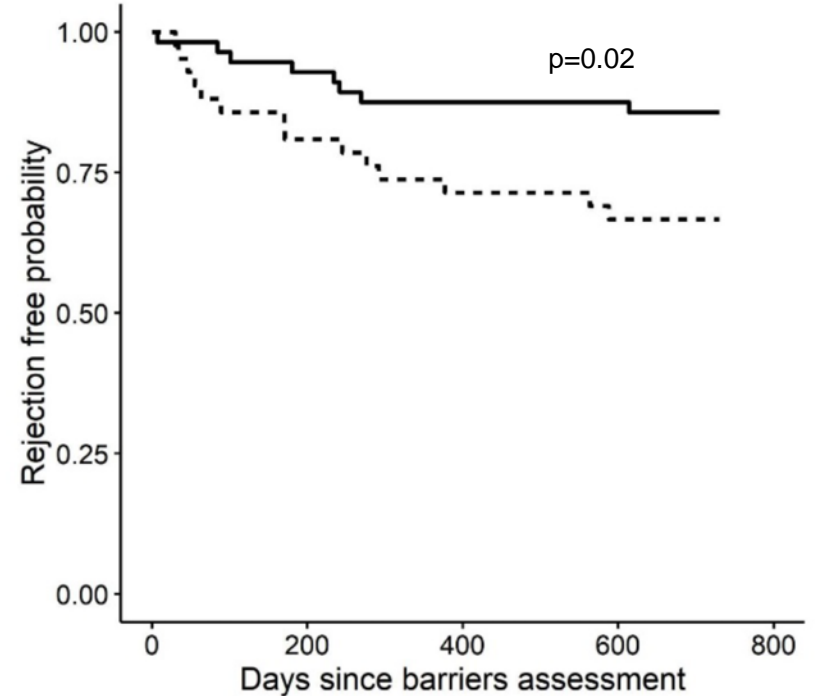
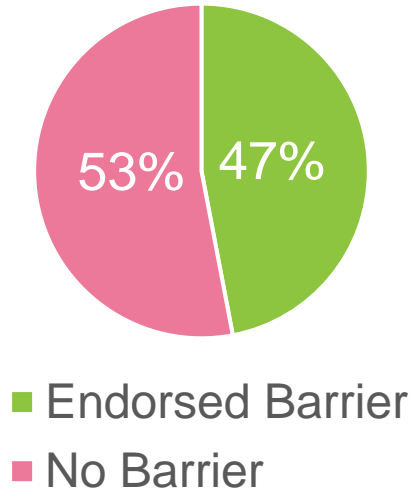
## Monthly Late Acute Rejection Rate (u-chart)



# Research with Clinical Data

# Results: Patient-Identified Barriers (n=98)

98 patients represented  $M(SD)$  age = 13.9 (6.4) years



— Patient did not identify a barrier - - Patient identified a barrier  
Varnell et. al., Peds Neph, 2020

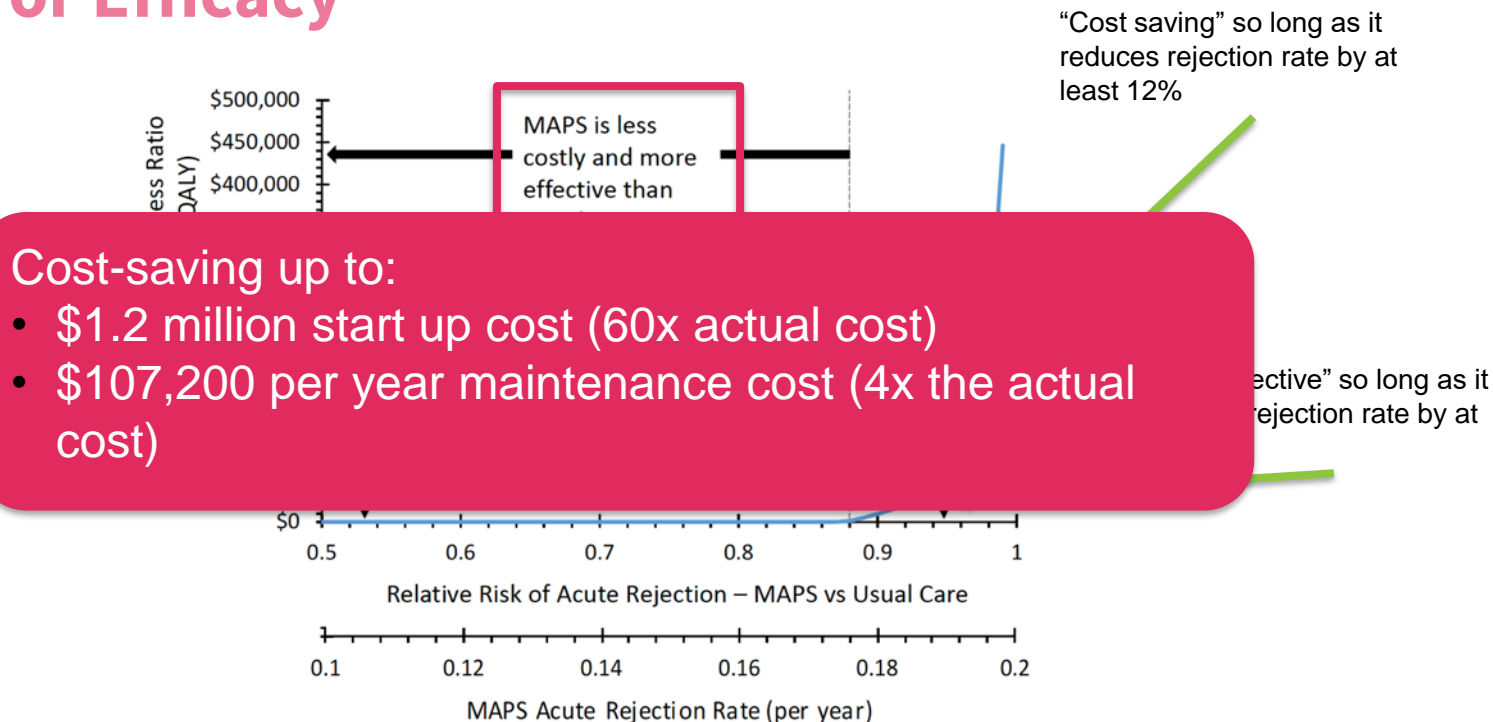
# Multivariable Analysis

**Table 4. Multivariable Survival Analysis: Incidence Rate Ratio of Late Acute Rejection**

<b>Risk Factor</b>	<b>Incidence Rate Ratio (95% CI)</b>	<b>p-value</b>
<b>Pre-MAPS (vs. Post-MAPS)</b>	0.50 (0.27-0.91)	0.02
<b>DSA History</b>	2.27 (1.12-4.57)	0.02
<b>Repeat Kidney Transplant</b>	1.65 (0.53-5.16)	0.39
<b>Deceased Donor</b>	0.58 (0.23-1.45)	0.24
<b>Minority Status</b>	0.56 (0.24-1.34)	0.19
<b>Prior Rejection</b>	1.37 (0.65-2.91)	0.41
<b>HLA Mismatch</b>	1.41 (0.63-3.20)	0.41
<b>Time Since Transplant</b>	0.87 (0.77-0.97)	0.02

Abbreviations: CI—Confidence Interval; CNI—Calcineurin Inhibitor; DSA-Donor Specific Antibody; HLA—Human Leucocyte Antigen; MAPS—Medication Adherence Promotion System

# MAPS is cost Saving and Cost-Effective over a wide ranges or Efficacy

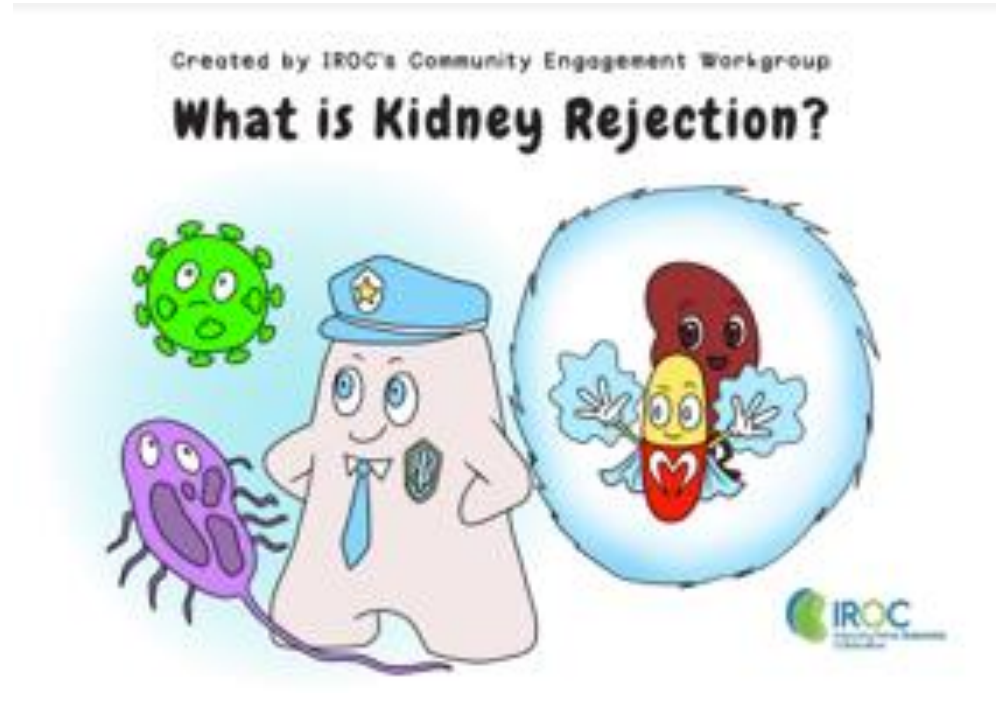
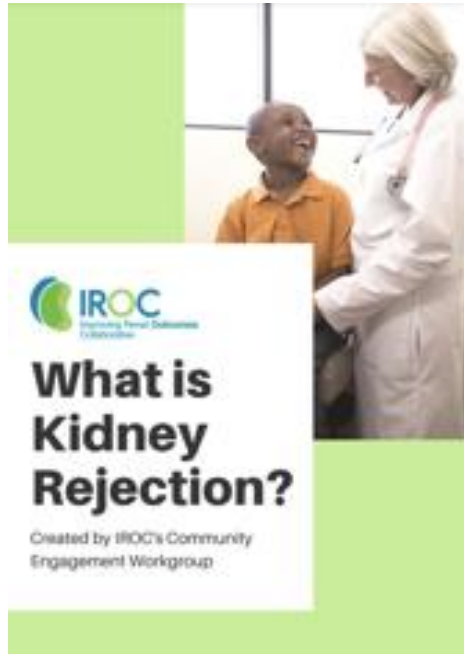


# Network Based Co-production and Spread

Improving Renal Outcomes Collaborative



# Educational Materials Coproduced with Patients, Families, and Clinicians



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

Children's  
MINNESOTA



Riley Hospital  
for Children  
Indiana University Health

Cincinnati  
Children's™  
changing the outcome together

NATIONWIDE CHILDREN'S  
When your child needs a hospital, everything matters.™

Boston  
Children's  
Hospital  
Until every child is well™

Cohen Children's  
Medical Center  
Northwell Health™

JOHNS HOPKINS  
CHILDREN'S CENTER

Children's  
Hospital of Pittsburgh  
of UPMC

The Children's Hospital  
of Philadelphia®

Nemours Children's Hospital

Children's  
Healthcare of Atlanta

Children's  
of Alabama™

PHOENIX CHILDREN'S  
Hospital



Mattel Children's Hospital

UCLA

Stanford  
Children's Health

UCSF Benioff Children's  
Hospitals

Seattle Children's  
HOSPITAL • RESEARCH • FOUNDATION



Children's Mercy  
HOSPITALS & CLINICS  
— Kansas City —

Children's Hospital Colorado

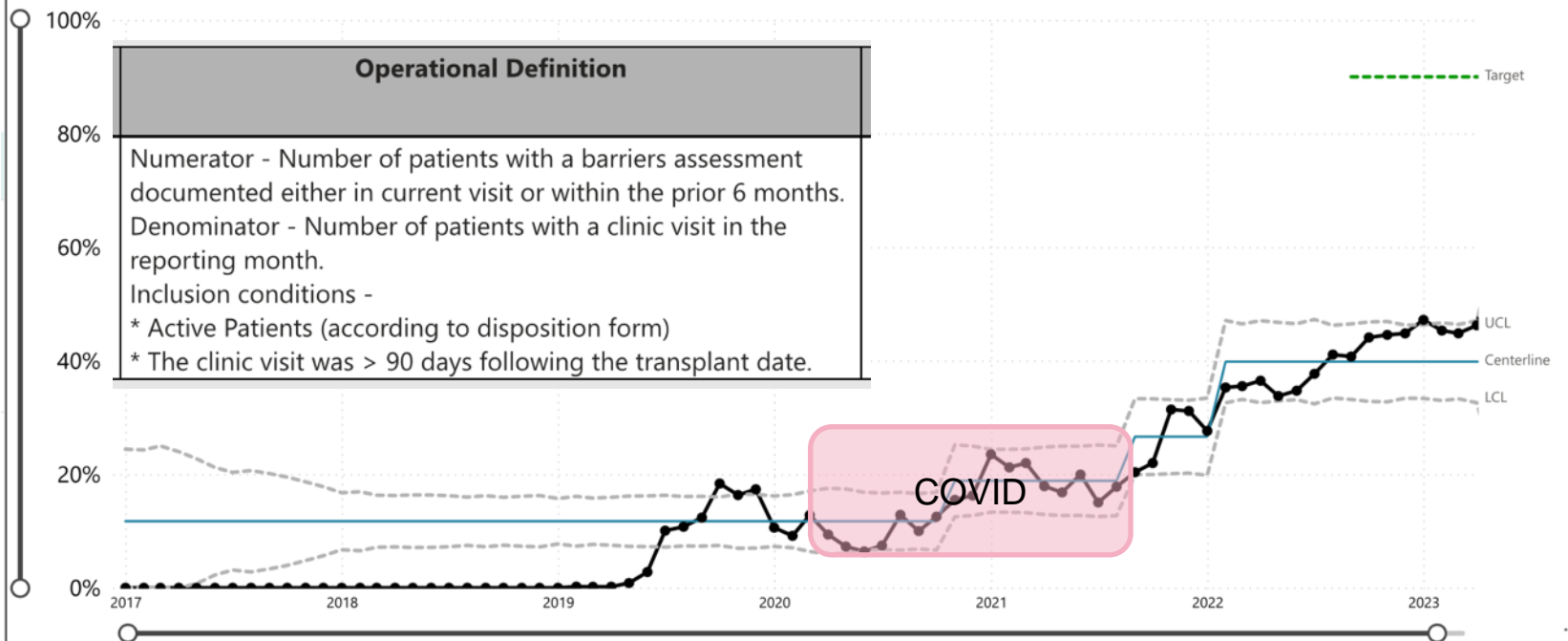
Arkana  
Children's

University of Iowa  
Stead Family  
Children's Hospital

SSM-Health  
Cardinal Glennon  
Children's Hospital



## Adherence Barriers Assessment - Network



	Indi	2021-Sep	2021-Oct	2021-Nov	2021-Dec	2022-Jan	2022-Feb	2022-Mar	2022-Apr	2022-May	2022-Jun	2022-Jul	2022-Aug	2022-Sep	2022-Oct	2022-Nov	2022-Dec	2023-Jan	2023-Feb	2023-Mar	2023-Apr
Assessr	80	87	130	133	105	145	173	151	152	167	147	216	198	194	192	233	243	208	225	191	
No Ass	313	309	284	294	275	266	314	263	298	314	243	310	288	246	239	287	272	251	277	222	
Total	393	396	414	427	380	411	487	414	450	481	390	526	486	440	431	520	515	459	502	413	

# Innovation and Scale

Developing a Digitally Enabled Adherence Platform for spread and scale to other patients with chronic illness

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PARTNERING TO ACHIEVE HEALTH, LONGEVITY, AND QUALITY OF LIFE

## INTERVENTIONS BY PACKAGE

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Rejection Prevention

Research

Central IRBs

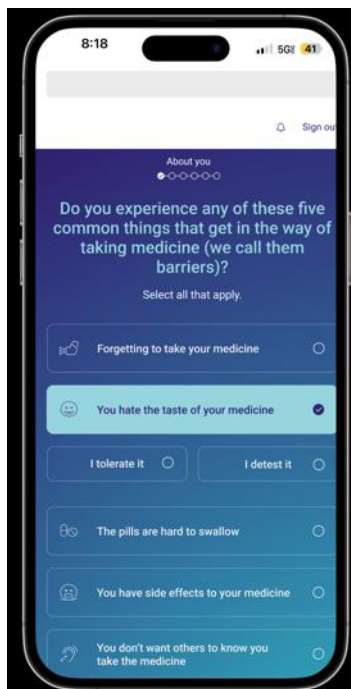
Explore Pediatrics vs Adult

Enhanced Solution Shop

IROC Exchange

Mentorship for Research

# Digitally Enabled Adherence Platform



DEAP Search

Dr. Roger Menezes

### SURVEY & REPORTING

Surveys completed  
8

Surveys overdue  
3

Clinical interventions  
4

Active barriers  
11

Patient Id	Username	Patient Name	Age	Active barriers	Intervention required	Care Team	Survey completed
23	Sam.Williams@gmail.com	Samuel Williams	15	The pills are hard to swallow	12/23/2022	Yes	elena.abelson@cchmc.org 11/23/2022
12	RebeccaC@gmail.com	Rebecca Cruz	11	The pills are hard to swallow	10/12/2022	Yes	elena.abelson@cchmc.org Overdue (5 days) Remind

#### PROFILE

**Rebecca Cruz** in CLINICAL INTERVENTION  
Username: RebeccaC@gmail.com  
Age: 11  
Gender: Female

#### BARRIERS

TYPE	DETAILS	IDENTIFIED ON	STATUS
The pills are hard to swallow		10/12/2022	Active
Hate the taste of medicine	Detest it	07/05/2022	Completed
Experiencing side effects	Tummy ache	07/05/2022	Completed

#### SURVEYS

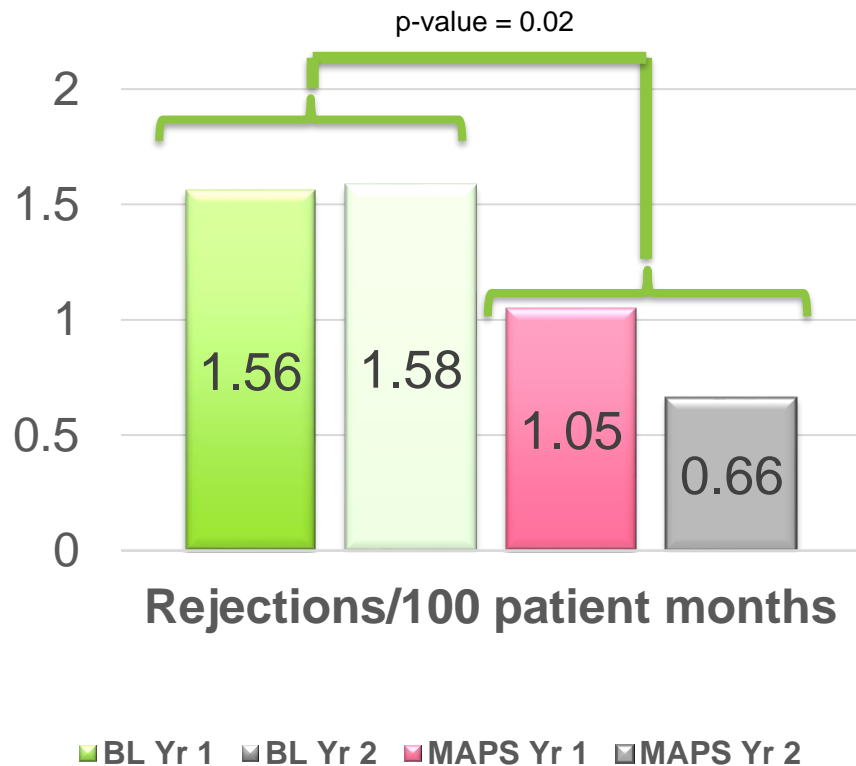
DUE DATE	BARRIERS	STATUS	ACTION
10/12/2022		Overdue	Remind
05/09/2022	Yes	Completed	
02/10/2022	Yes	Completed	

See all

3	SoniaP@gmail.com	Sonia Castello	14	None	10/12/2022	No	susie.anderson@cchmc.org Overdue (3 days) Remind
15	ABLove@gmail.com	Abraham Love	15	Hate the taste of medicine	12/23/2022	Yes	elena.abelson@cchmc.org 11/23/2022
32	Sam.Williams@gmail.com	Samuel Williams	15	The pills are hard to swallow	12/23/2022	Yes	elena.abelson@cchmc.org 11/23/2022

# **Learning Health System VS. Traditional Approach**

## MAPS

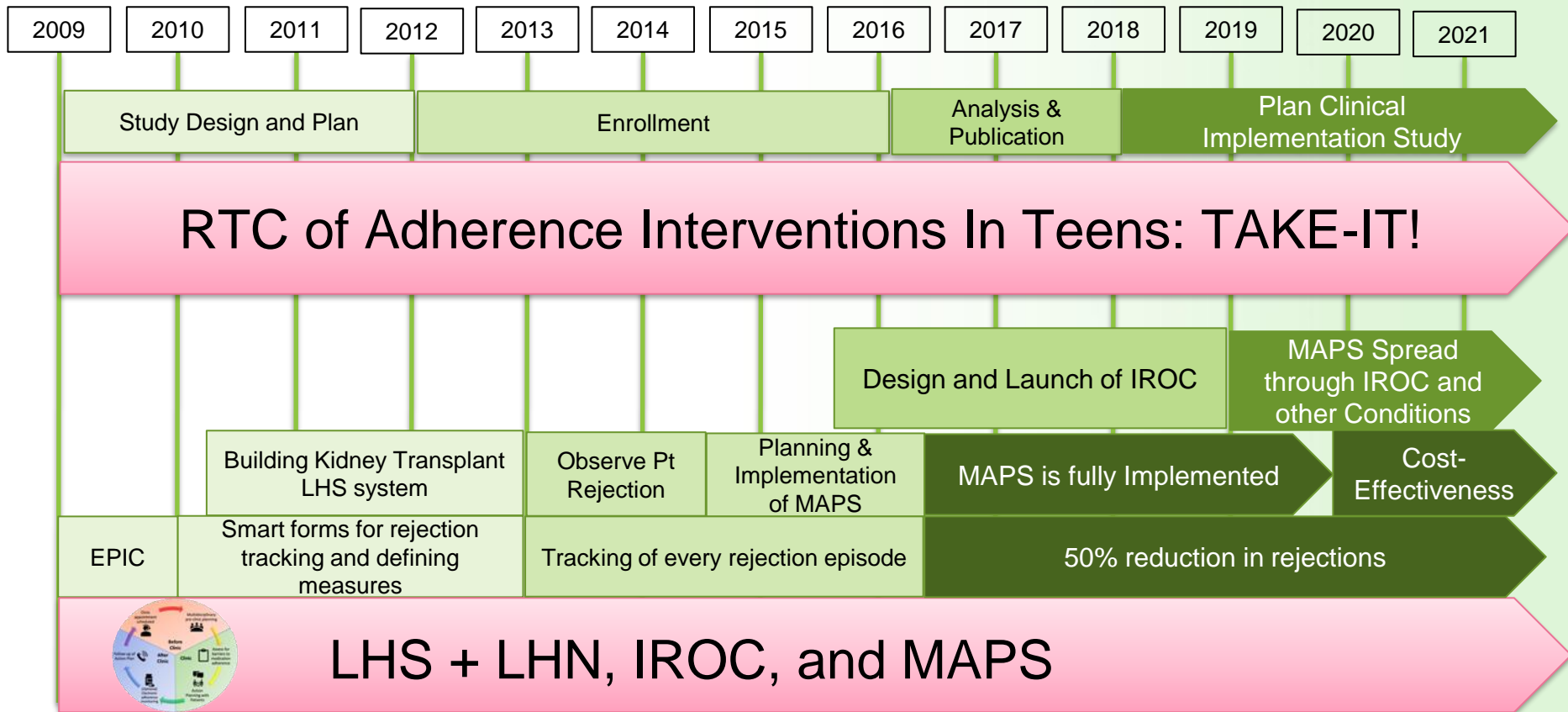


## TakeIT! Multi-center RCT





# LHS Vs. Traditional Approach



# How?



# Proven Methodology

R&D: First 15 years—Developing and Proving the Methods

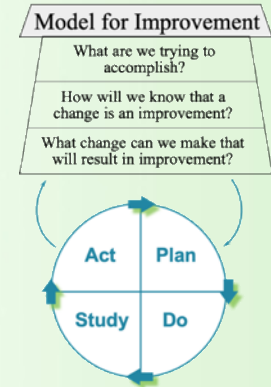
# Learning Health Network



Community  
(ALL stakeholders  
“Actors” engaged social  
network)



Technology/Registry  
(infrastructure for  
data/knowledge sharing,  
“Commons”)

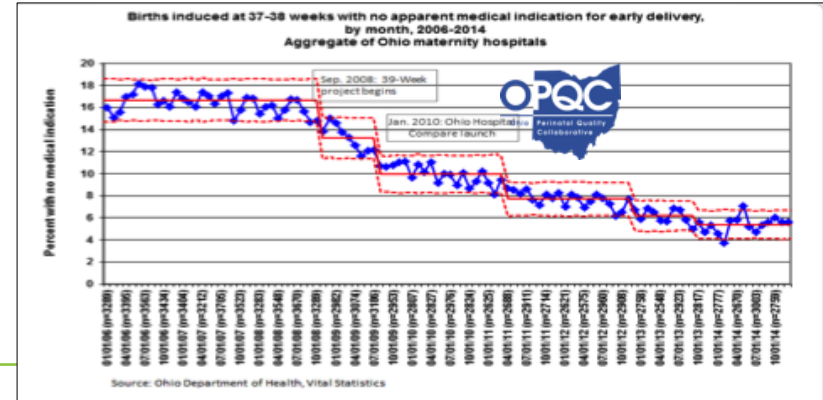
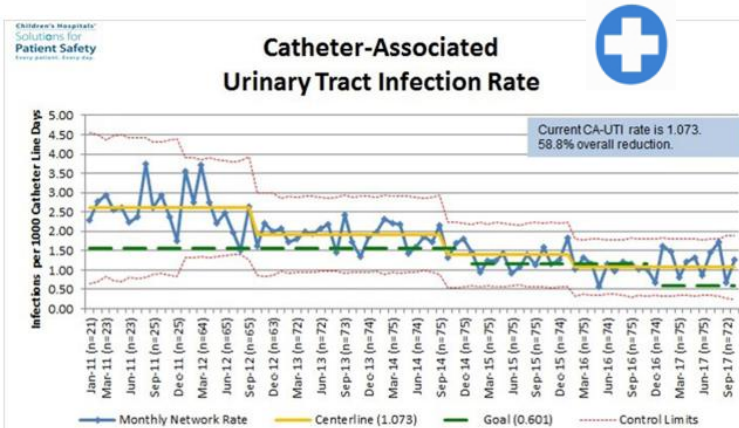
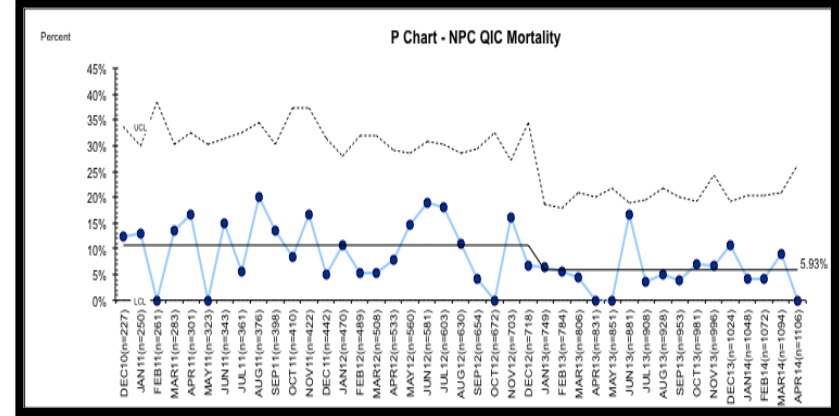
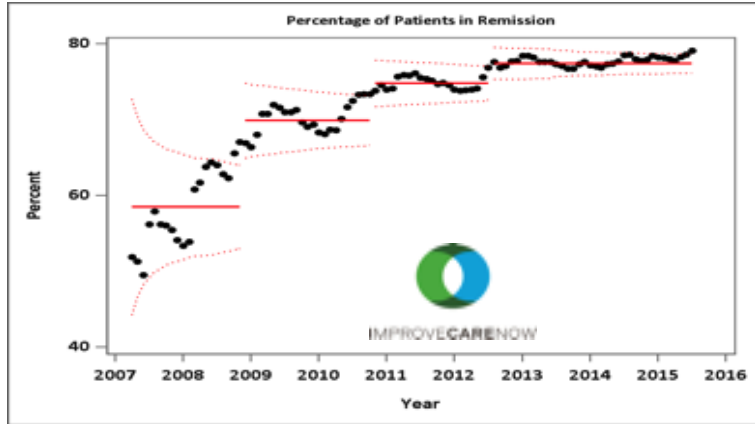


Methodology  
(Processes and Policies)

# Our Community of Networks



# Results



# Barriers to Scale

Designing for Scale: Looking to the Future



# Design Challenges



1. How to build and govern a thriving, collaborative community of networks
2. A business and financial strategy for growing and sustaining the community and individual networks.
3. How to use technology, data, and analytics to facilitate innovation, sharing, improvement, and research
4. How to grow and enhance co-production
5. How to build scalable systems improvement capability
6. How to accelerate research and learning

***“Luck is the residue of design” - Branch Rickey***

***American Baseball Player – Broke the color barrier by signing Jackie Robinson***

# Building and governing a community of networks

## Existing Networks

1. Hospital Safety (Solutions for Patient Safety)
2. IBD (ImproveCareNow)
3. Kidney Transplant (Improving Renal Outcomes Collaborative)
4. Ohio Perinatal Quality Collaborative
5. Asthma Learning Health System
6. Hypo-plastic left heart syndrome (National Pediatric Cardiology Quality Improvement Collaborative)
7. Fontan Outcomes Network
8. Community Health (All Children Thrive Cincinnati)
9. Congestive heart failure (ACTION)
10. Hospital cardiac care (PAC 3 and 4)
11. Cystic Fibrosis Learning Network
12. Autism Learning Health Network
13. Epilepsy Learning Health Network
14. Pancreatic Cancer (Canopy Cancer Collective)
15. Pediatric rheumatology collaborative improvement network (PR-COIN)
16. Sickle Cell Network
17. Bipolar Disorder (life span)

## Prospective Networks

Adult kidney transplant

Posterior urethral valves (pediatric)\*

Adult safety

Cancer

- Bone marrow transplant (life span)\*
- Oncology survivorship (life span)\*
- BRCA Breast Cancer
- Multiple myeloma
- Colon cancer

Mental/behavioral health

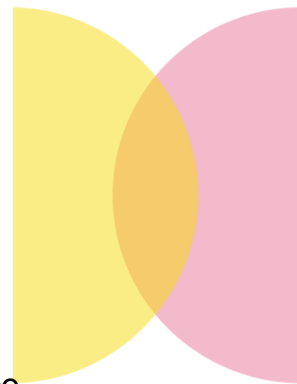
- Anxiety disorders
- ADHD
- Depression

Cross-cutting networks

- Equity
- Adherence
- Emotional health and resilience

Public Health Preparedness

Trach dependent children



# Collaboration, Business and Financial Barriers

- One-at-a-time model does not scale
  - “Does there need to be a new network for every condition? How could hospitals join more networks?” Tina Cheng, MD, MPH – Dept. Chair, CCHMC
- Limited efficiency
  - Inter-related conditions
  - Cross-cutting needs (e.g., mental health, adherence)
  - How to prioritize new networks for biggest impact
- Network infrastructure not yet robust or shared
- No stable financing for primary network benefit of better health outcomes or “byproducts” (e.g., research)



# Design Challenges

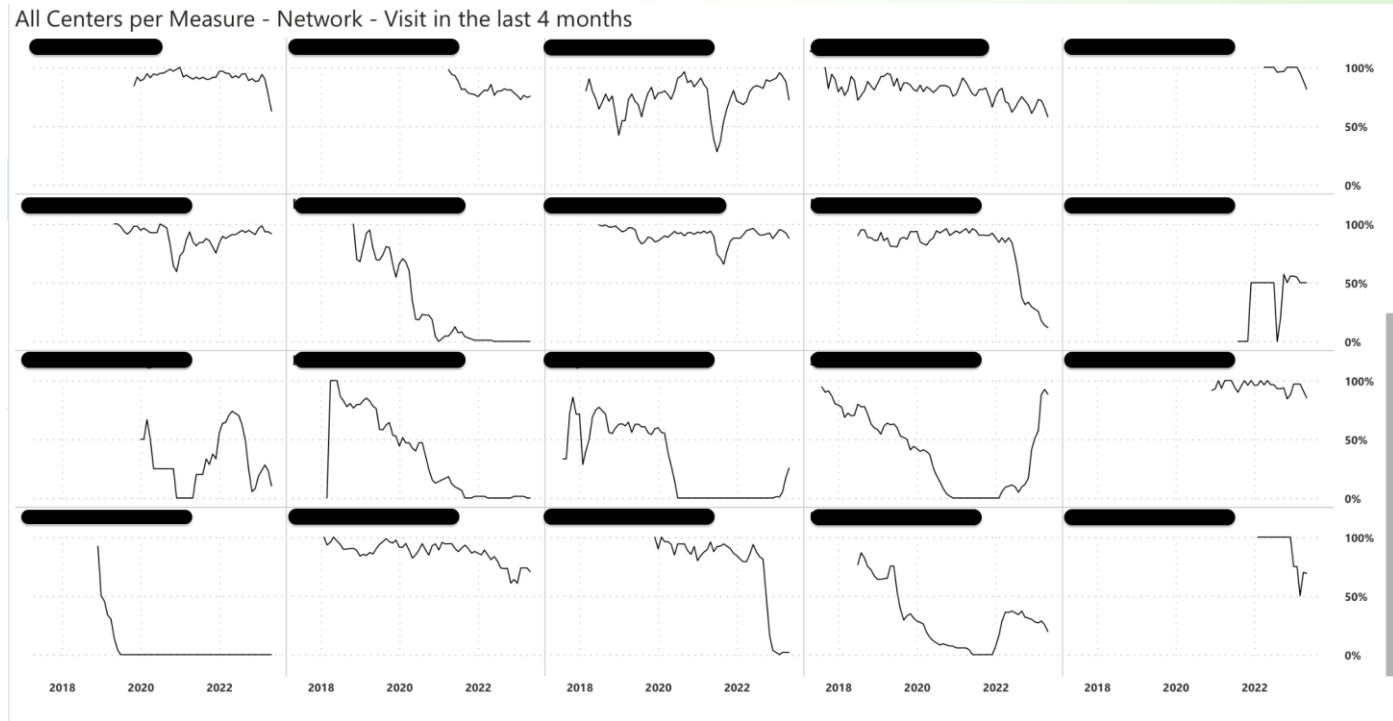


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# % Patients with Visit Entered in Last 4 Months By Center



# Technology and Analytic Barriers

- Excessive burden of data capture
  - Including local IT effort to implement tools for data capture (e.g., FHIR)
- Cost of building and maintaining registries
- Not taking full advantage of existing and new data sources
  - More advanced analytics as part of care planning
  - Tools to support knowledge sharing (e.g., recommender engines for QI)
  - New data sources (PROs, sensors, data linkages – public health + clinical + prescription)

# Design Challenges



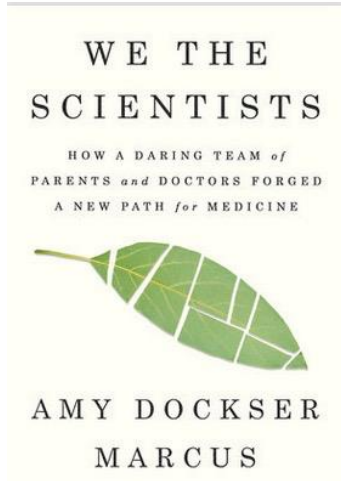
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# Growing and enhancing co-production

## Research



## Care

### Self-dialysis in Sweden



## Innovation



**Despite these advances, still too hard for all patients to participate**

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# Design Challenges



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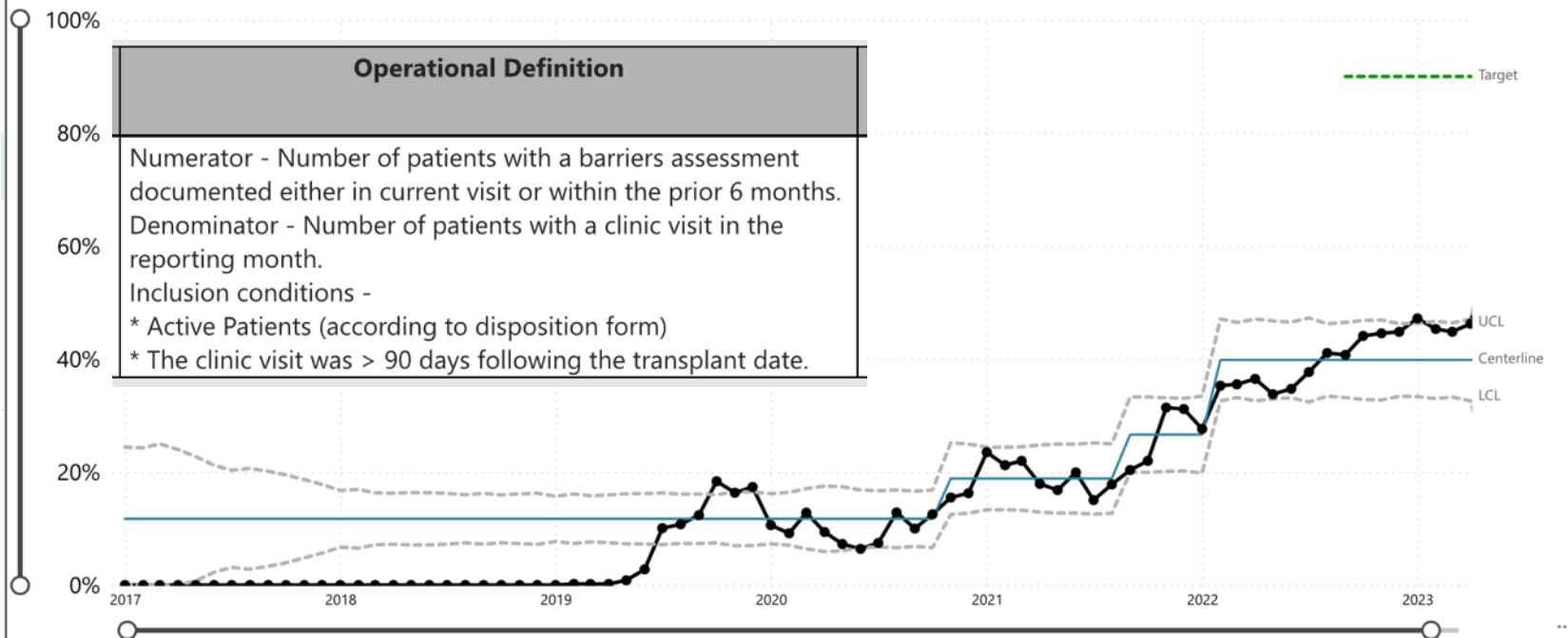
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# Scalable Quality Improvement Capacity

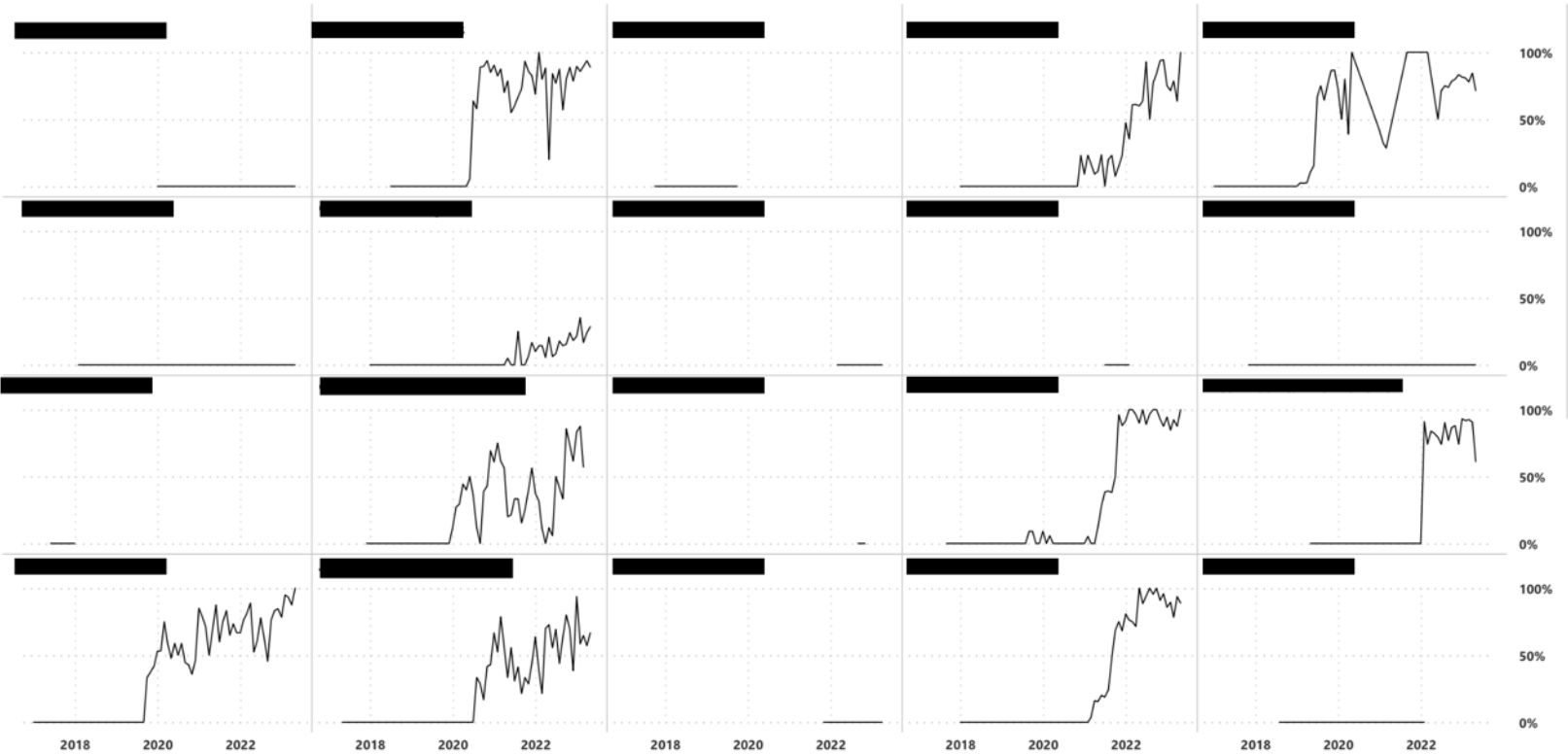
Complex Environments with Competing Priorities

## Adherence Barriers Assessment - Network



▲	Indi	2021-Sep	2021-Oct	2021-Nov	2021-Dec	2022-Jan	2022-Feb	2022-Mar	2022-Apr	2022-May	2022-Jun	2022-Jul	2022-Aug	2022-Sep	2022-Oct	2022-Nov	2022-Dec	2023-Jan	2023-Feb	2023-Mar	2023-Apr
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Total	393	396	414	427	380	411	487	414	450	481	390	526	486	440	431	520	515	459	502	413	

All Centers per Measure - Network - Adherence Barriers Assessment



Select a Measure

Adherence Barriers Assessment

Select a Center

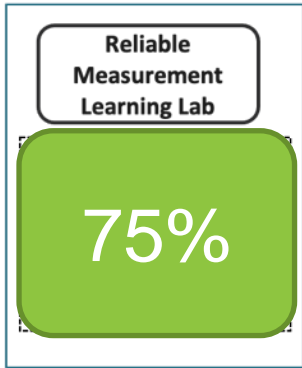
All



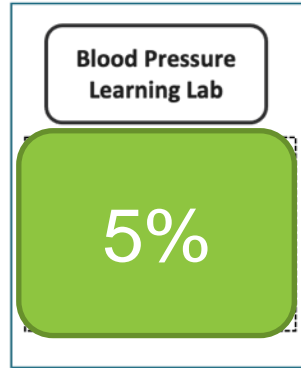
# IROC Pathway to Mastery



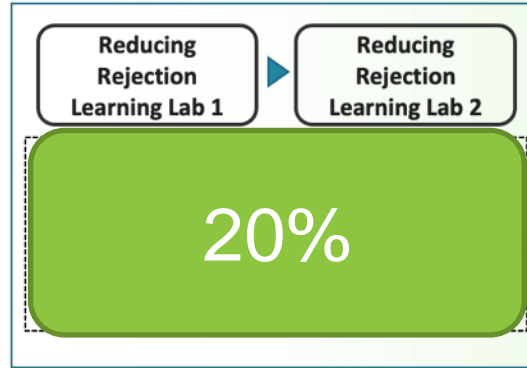
Fundamentals



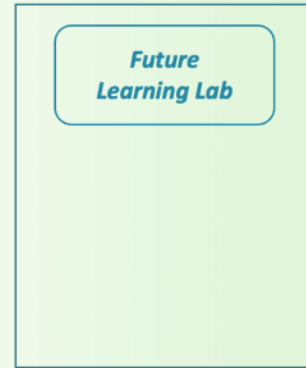
Achieve Improvement



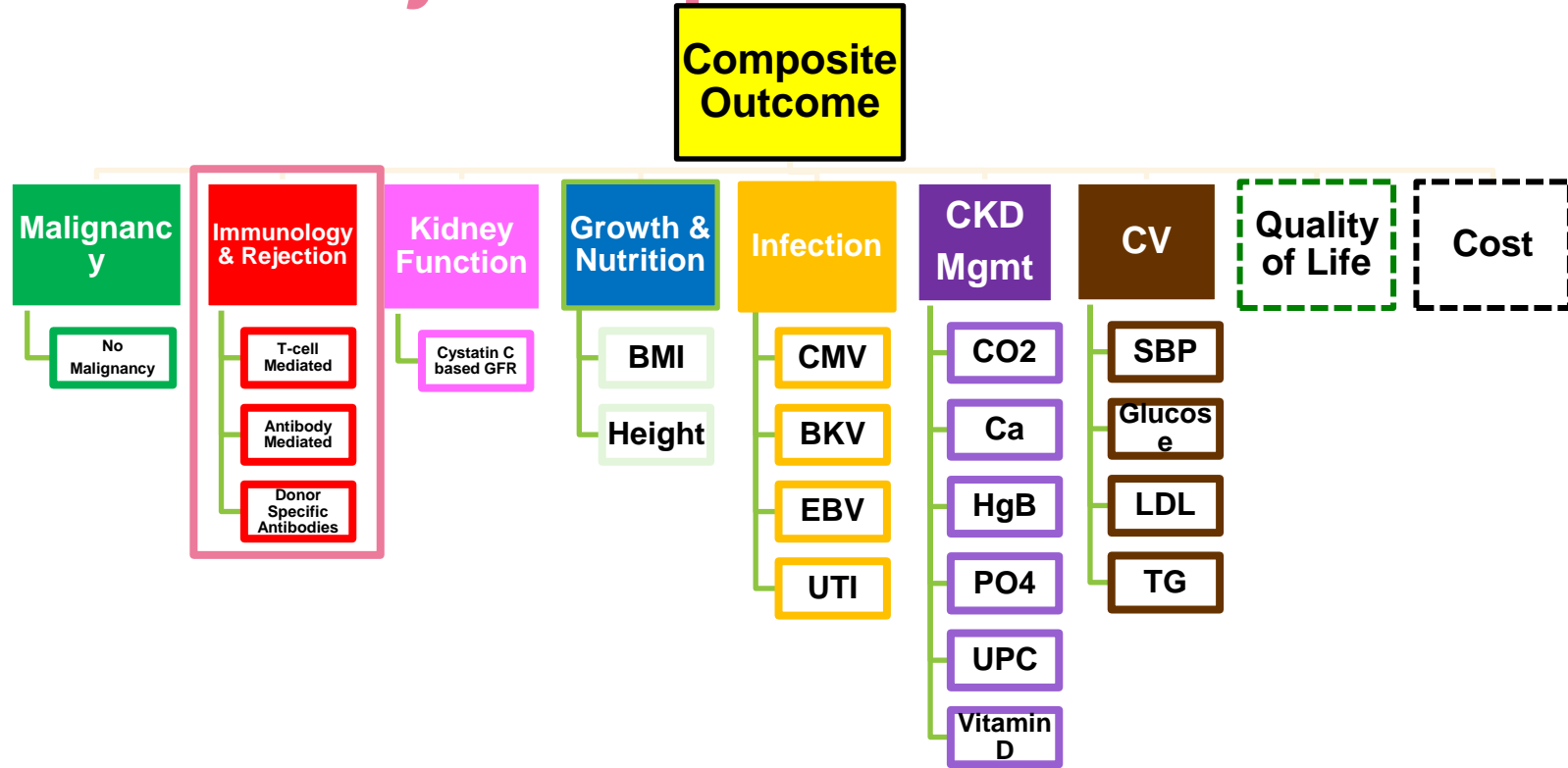
Reducing Rejection



Innovators



# Kidney Transplant Ideal Outcome



# Constraints to Scaling Improvement Capability

- Workforce: Limited improvement capability in many care centers
  - Staff turnover
  - Lack of staff
- QI competencies and execution: Discipline and process to apply methods at a high level
- Knowledge sharing: Re-inventing improvement projects
- Organizational incentives: Participation in QI is considered “Extra” in current payment environment

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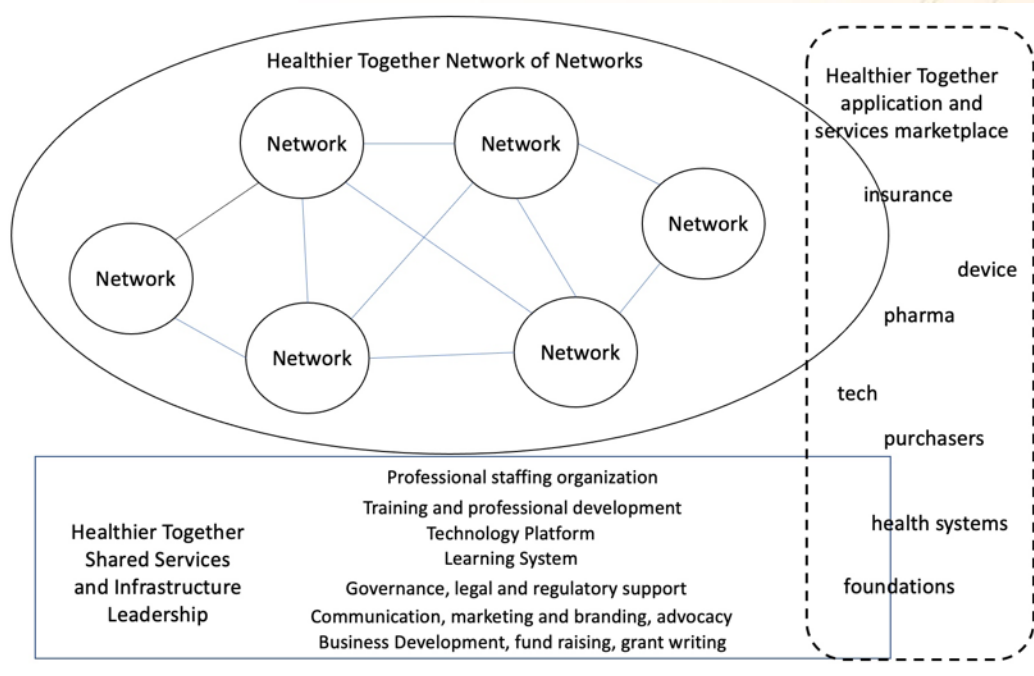


# Barriers to Accelerating Research and Learning

- Variation in research infrastructure across networks and care centers
  - Administrative friction for data sharing (time to contract, policies and processes to steward data)
  - Researchers usually determine priorities
  - Incentives for promotion do not favor collaboration
  - Constraints on full patient participation
    - Training
    - Money to fund patient research priorities
    - Patients forced to volunteer to participate
-

# The Opportunity

# Learning Network Eco-System



## Domains:

1. Professional staffing organization
2. Training and Professional Development
3. Technology Platform
4. Learning system
5. Governance, Legal, Regulatory
6. Communication, marketing, branding, advocacy
7. Business Development, Fund Raising, Grant writing
8. Application and Services marketplace



HEALTHIER  
TOGETHER

# Questions/Discussion

