

## 2020 Southwest First Episode Psychosis Conference

# Building a Learning System of Care: Using Data & Outcomes to Advance Early Psychosis Care

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**11:00 – 12:00 PM CST**

# Evaluating Coordinated Specialty Care

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# Objectives

- What is program evaluation?
- Why is it important for CSC programs?
- What are the barriers to implementing program evaluation?
- Which data should be collected?
- How should data be collected?

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# What is Program Evaluation?

“The systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development” (CDC, 2012)

- Practical and Feasible
- Useful
- Ongoing
- Systematic
- Collaborative
- Flexible



**Evaluation** is designed to *improve*  
**Research** is designed to *prove*

# Why Collect Data for Program Evaluation?

## Client level

- Monitor individual progress
- Clinician feedback

## Program level

- Identify areas for improvement
- Determine if strategies for improvement are successful (logic model)
- Use results for outreach and advocacy

# Challenges and Barriers

Burden is the main barrier to conducting effective program evaluation

- Clinician time
- Client burnout (repetitive questions, extra appointments)
- Coordinating (data entry, management and reporting)
- Cost

Some challenges include...

- Engagement and follow-up completion
- Reliability of data

**\*This is why consideration of which data  
to collect and how to collect it is so  
important!\***



# Which Data to Collect

Utilize existing data when possible – what is required clinically

- E.g. most insurance reimbursements require treatment plans at 6 months that include formal assessment of safety risk (suicide)

Get Stakeholder input

- Clients and their families, clinicians, agency/organization supporting the CSC program, county and state level policy makers

Select outcome measures that are useful for multiple purposes

- What is important to families may or may not be important to state level policy makers
- Prioritize outcomes that overlap

Clinician and self report scales

- Reduces redundant interviews with clients by third party
- Can allow for comparison of perspectives





# Which Data to Collect

Common domains for CSC evaluation include:

- Referral Processes and DUP
- Clinical Symptoms
- Level of Functioning
- Engagement and Service Utilization
- Demographic and Socioeconomic Characteristics
- Fidelity to CSC Model

# Which Data to Collect

Guides for selecting measures or variables based on validity, burden (time for completion), commonality with other reporting requirements...

- SAMHSA – NOMS
- PhenX Toolkit
- NASMHPD – Use of Performance Measures Guide
- Evaluation questions checklist for program evaluation (Wingate & Schroeter, 2007)

# How to Collect Data

Utilizing existing Electronic Health Record (EHR) platforms

## Pros

- Reduces redundant data entry
- Makes outcomes accessible for clinical use

## Cons

- Not all EHR systems allow for this (strictly clinical purposes)
- May take a long time to set up new forms in EHR systems
- May be difficult to extract data in the correct format or when needed
- Multiple programs may not have the same EHR system

# How to Collect Data

REDCap or similar web-based platforms (Qualtrics)

## Pros

- Can be HIPAA compliant
- Are user friendly
- Survey links can be sent to clients/clinicians
- Set up automatic alerts for re-assessment

## Cons

- Additional platform for clinicians
- Requires FTE staff for designing, tracking, IT assistance
- Needs to be re-entered into EHR for clinical use



# How to Collect Data

## Other considerations...

- IRB and Consents
- Compensation as incentive
- Time frame for collection and entry
- Using MHBG funds for FTE coordinator (non-billable) or include in bundled care/case rate package



# Taking Evaluation to the System Level

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August 4, 2020

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# Objectives

- Why evaluate at a system level
- Elements of a learning healthcare system
- Measuring fidelity to practice models
- Examples from Texas
- The Early Psychosis Intervention Network (EPINET)



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# Silos and Sloths

- The promise of early psychosis care
- The challenge of the isolated program
- The traditional research paradigm is costly and slow
- Complexity of integrating new findings
- Cost of care is ever escalating

Need a new way!





# A Learning Healthcare System

*A learning health care system is one in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience.*

Roundtable on Value and Science-  
Driven Health Care, 2012

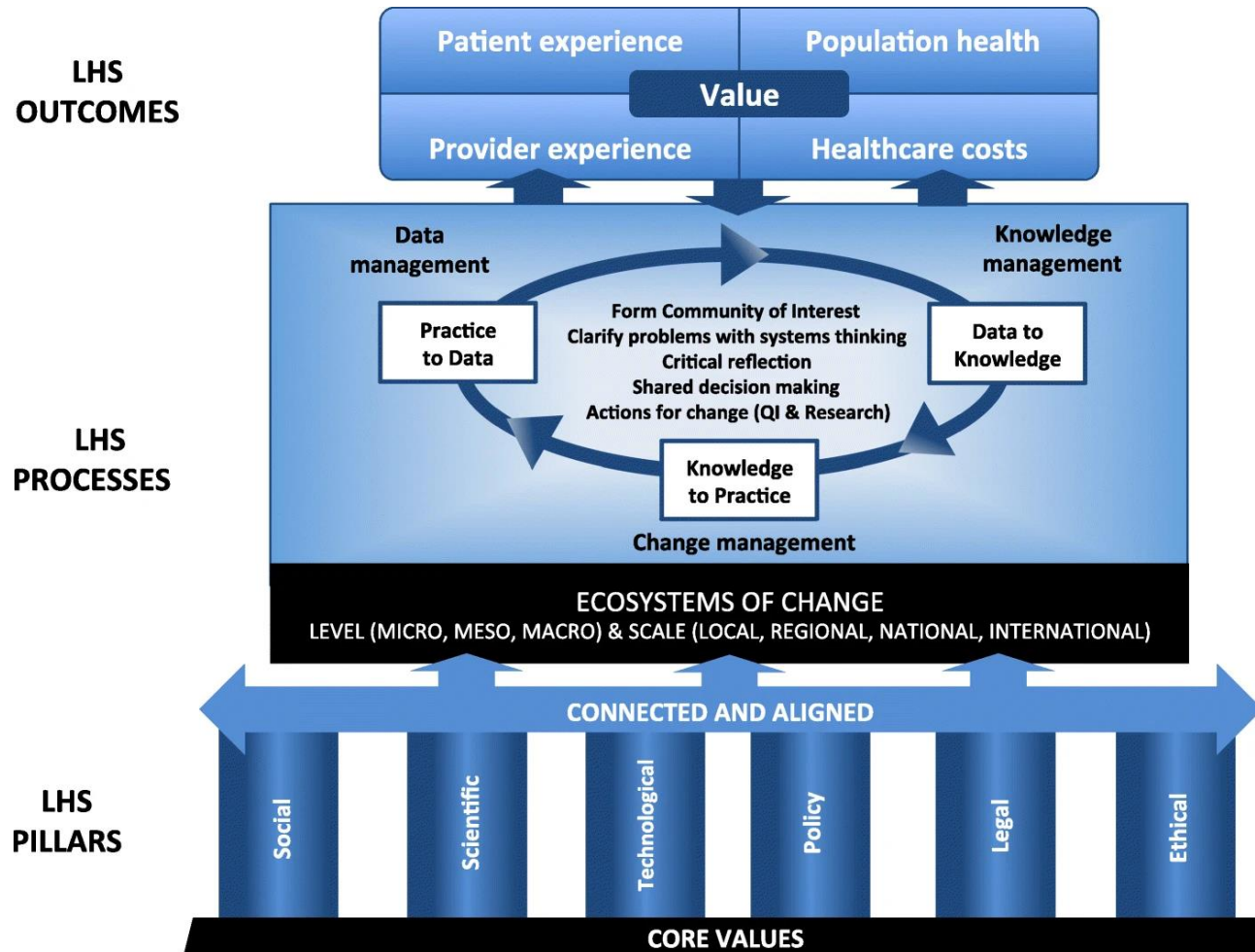


# Qualities of a Learning Healthcare System





# Qualities of a Learning Healthcare System





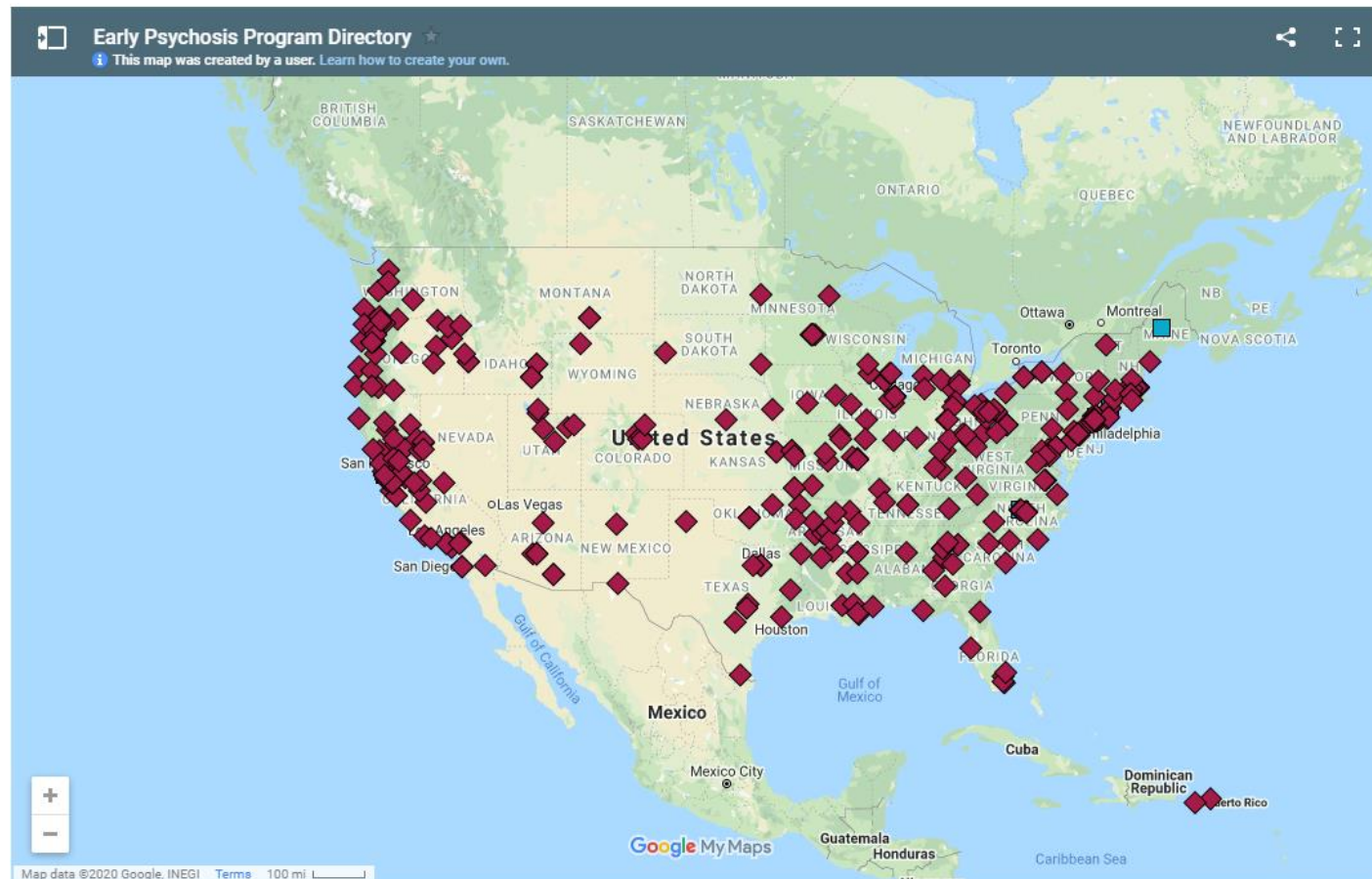
# How Do We Begin?

- Collaborative partnerships between providers, researchers, individuals in care and their families, and funders
- Shared measurement and data structures
- Data available in real-time to inform decision-making
- System for knowledge development
- Processes/structures for organizing, disseminating, incorporating knowledge in practice
- Structures to incorporate knowledge into shared decision making
- Policies and funding that aligns with best practice and promotes value





# Where Do We Start to Understand our System for Early Psychosis Care?



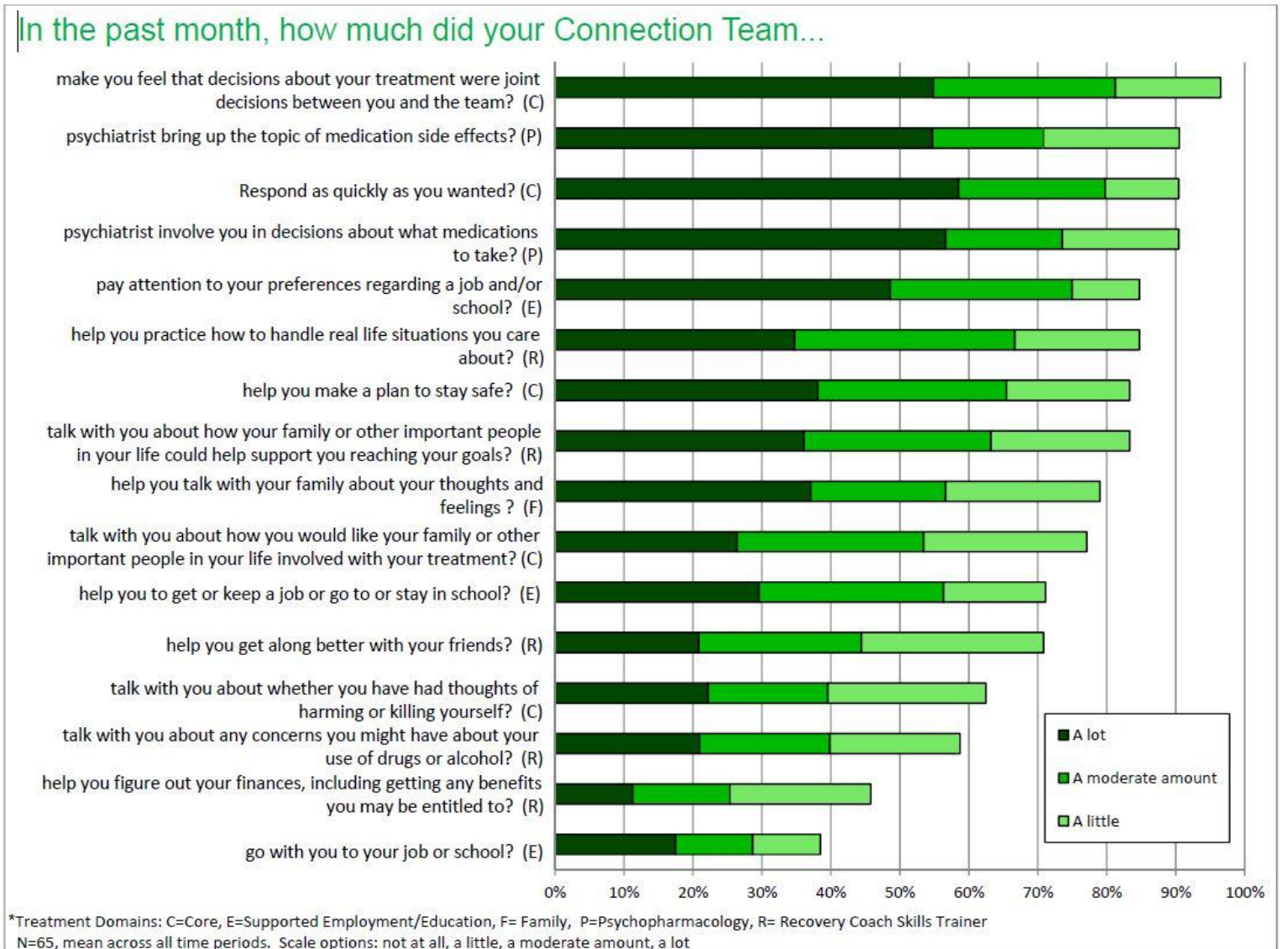


# Understanding Program Qualities: Exploring Fidelity

- Coordinated Specialty Care
  - First Episode Psychosis Fidelity Scale (FEP-FS; Addington, et al., 2016)
  - EASA Practice Guidelines (Melton, et al., 2013)
  - OnTrackNY
  - RAISE Connections (Essock, et al., 2015)
  - EDEN (Birchwood, et al., 2006)
- Specific Intervention-Level
  - IPS for Young Adults (IPS-Y)
  - Fidelity to IRT
  - CBT-P
  - Medication guidelines



# Measuring the Perspectives of Young People



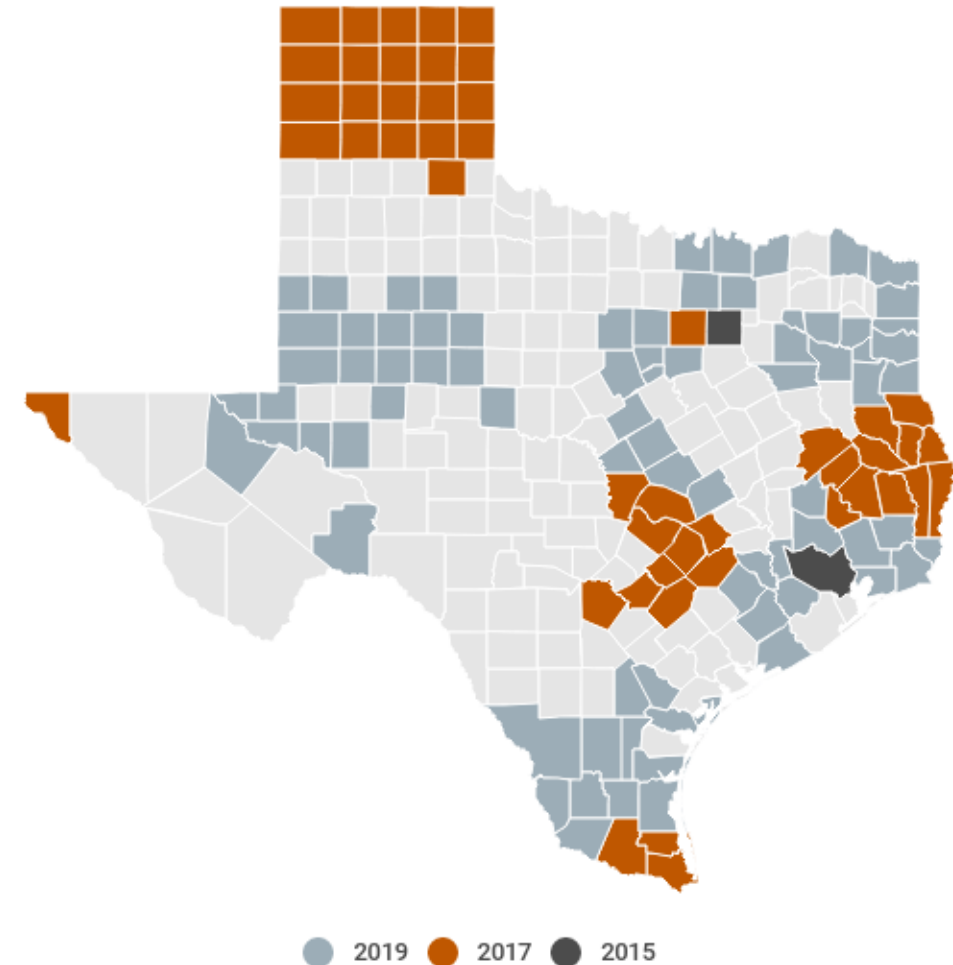
Essock, et al., 2015





# Case Study: Early Psychosis in Texas

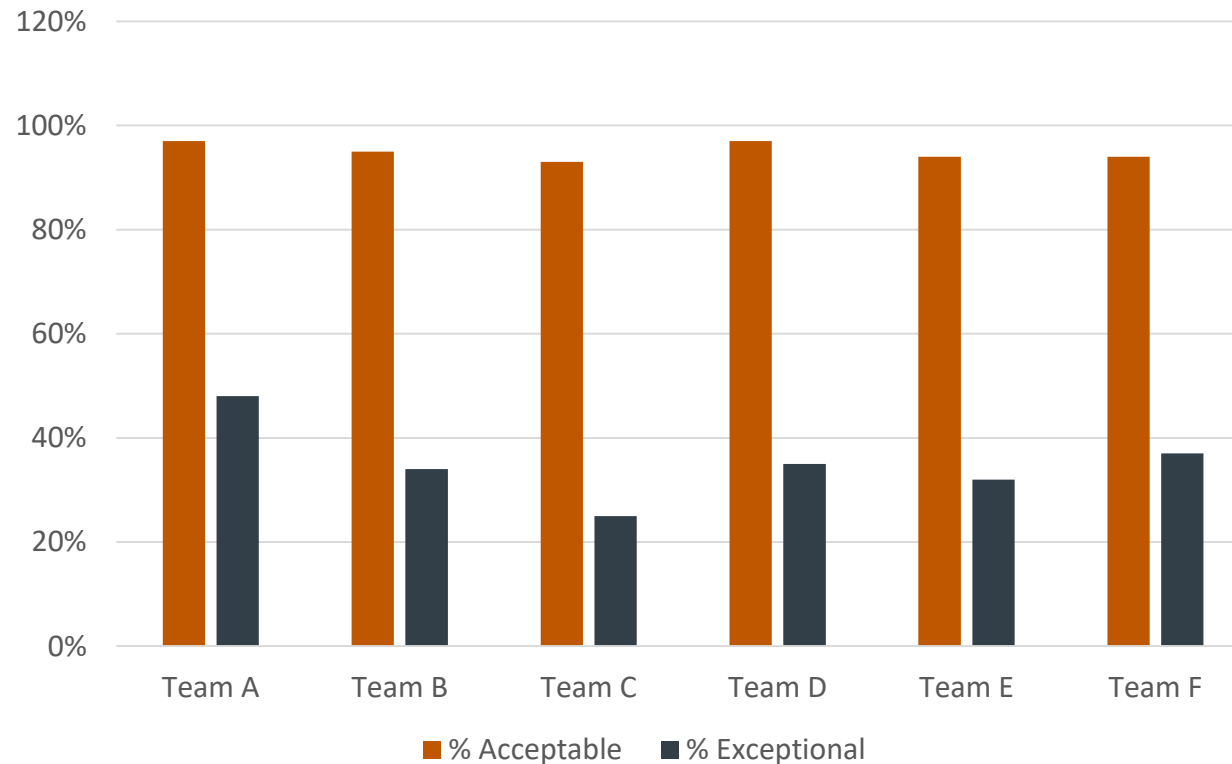
- 23 CSC programs (27 teams)
- OnTrack model
- MHBG funding
- Ages 15-30
- Include affective psychosis
- Beginning the evaluation journey



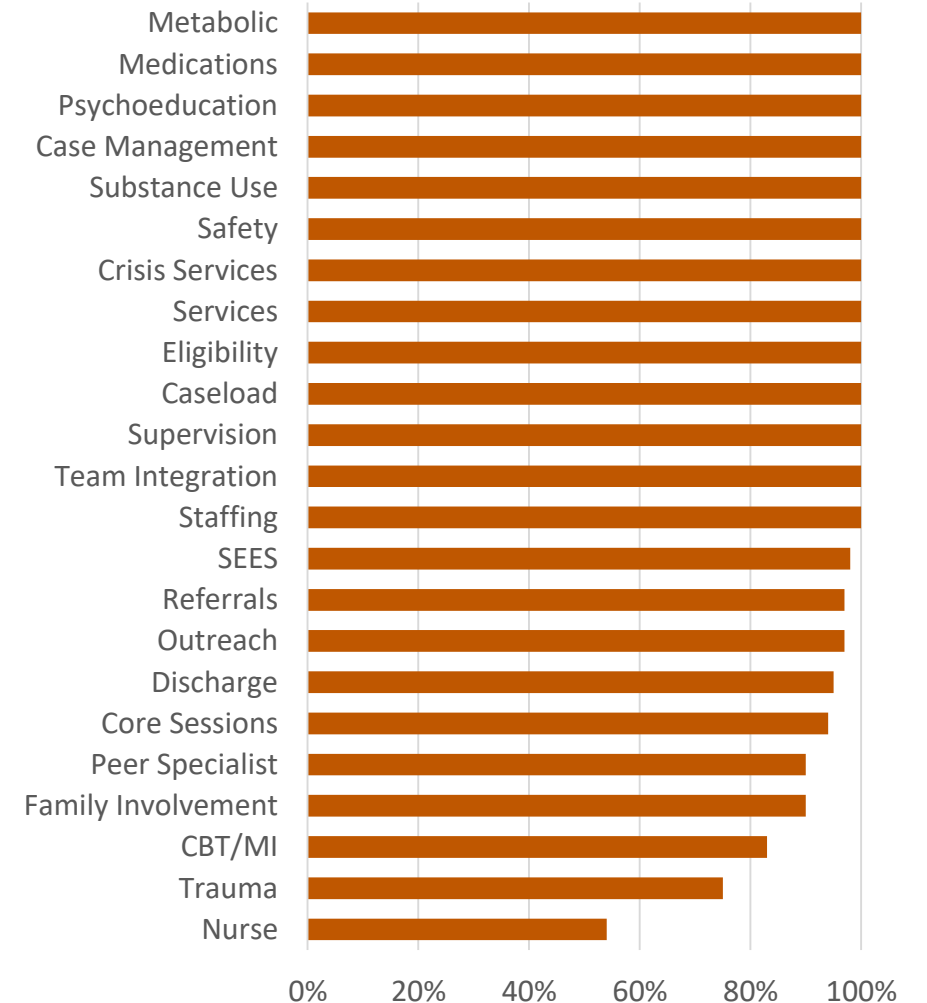


# Program Fidelity

Site Scores on OnTrack Fidelity Scale



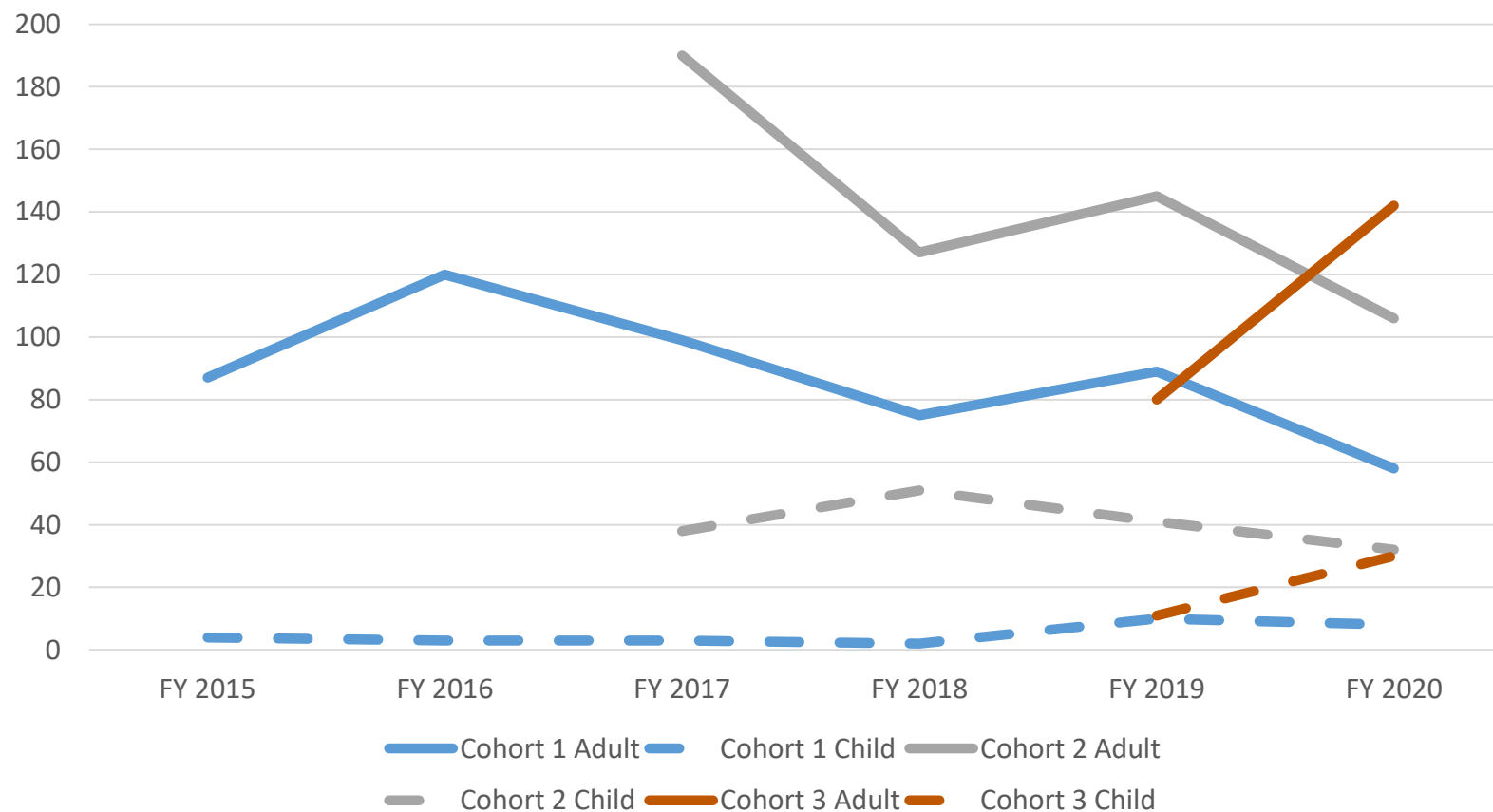
Subscale Fidelity Scores: Acceptable





# Enrollment of Youth in CSC

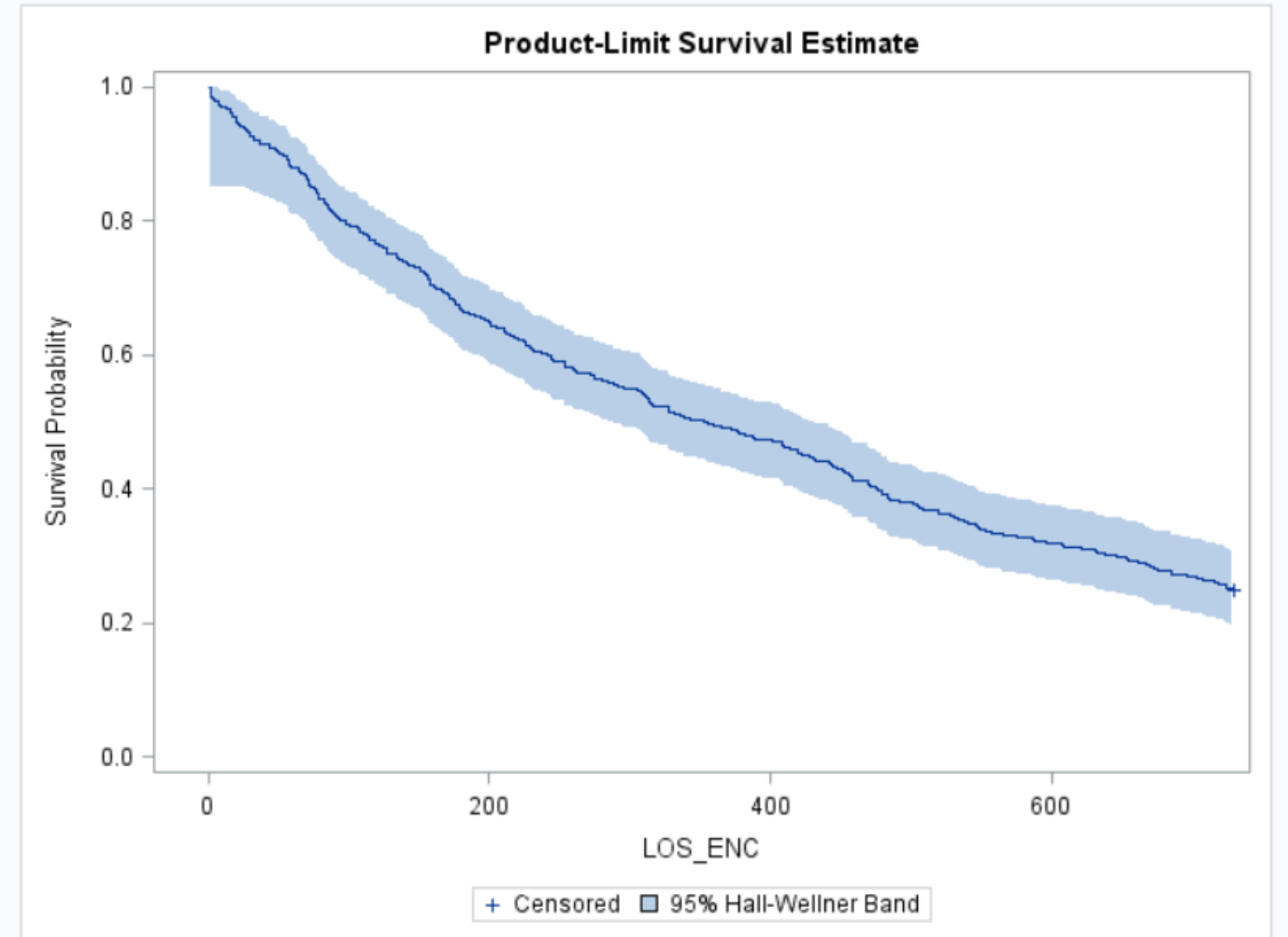
Qualitative interview data suggested that participants in newest cohort were more seriously impaired.





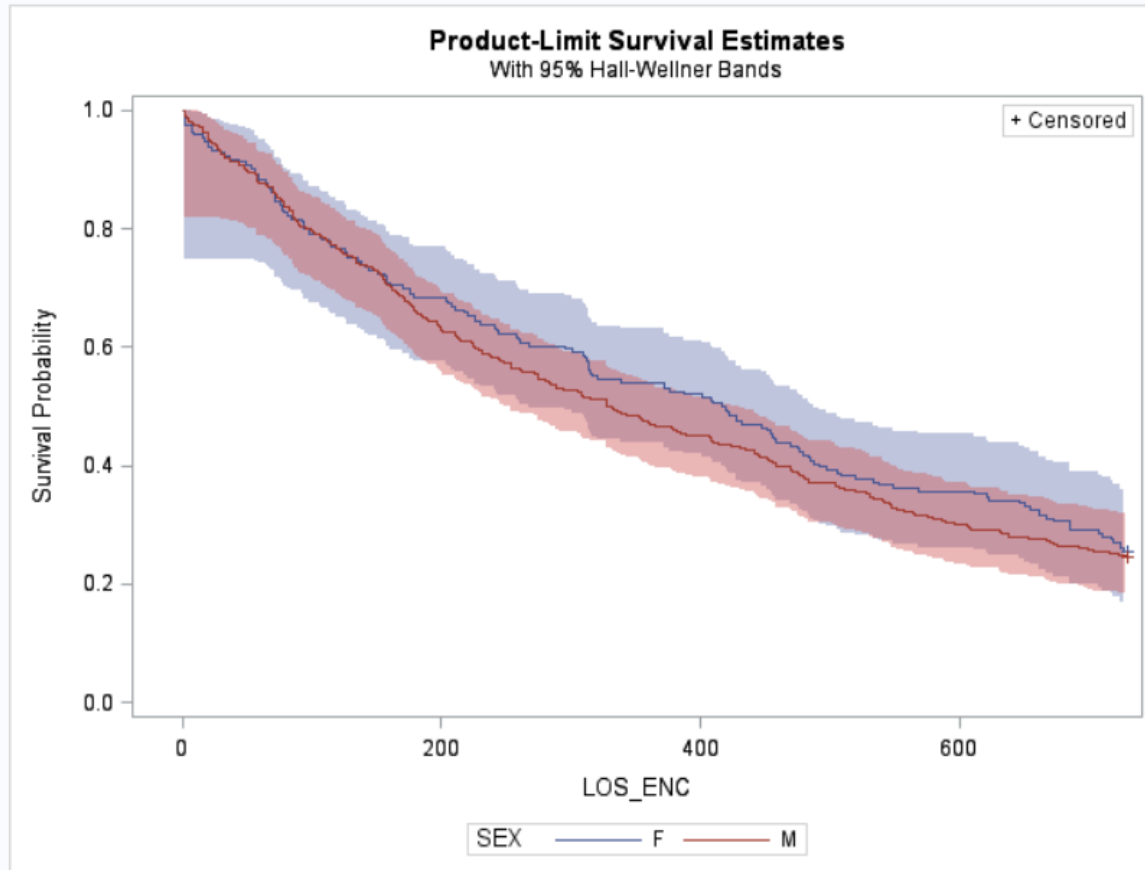
# Program Retention

- Retention in the program for up to 2 years (censored after 2 years)
- 25% drop out by Day 134
- 50% drop out by Day 354
- 75% drop out by Day 730 (end point) / 25% continue beyond 2 years

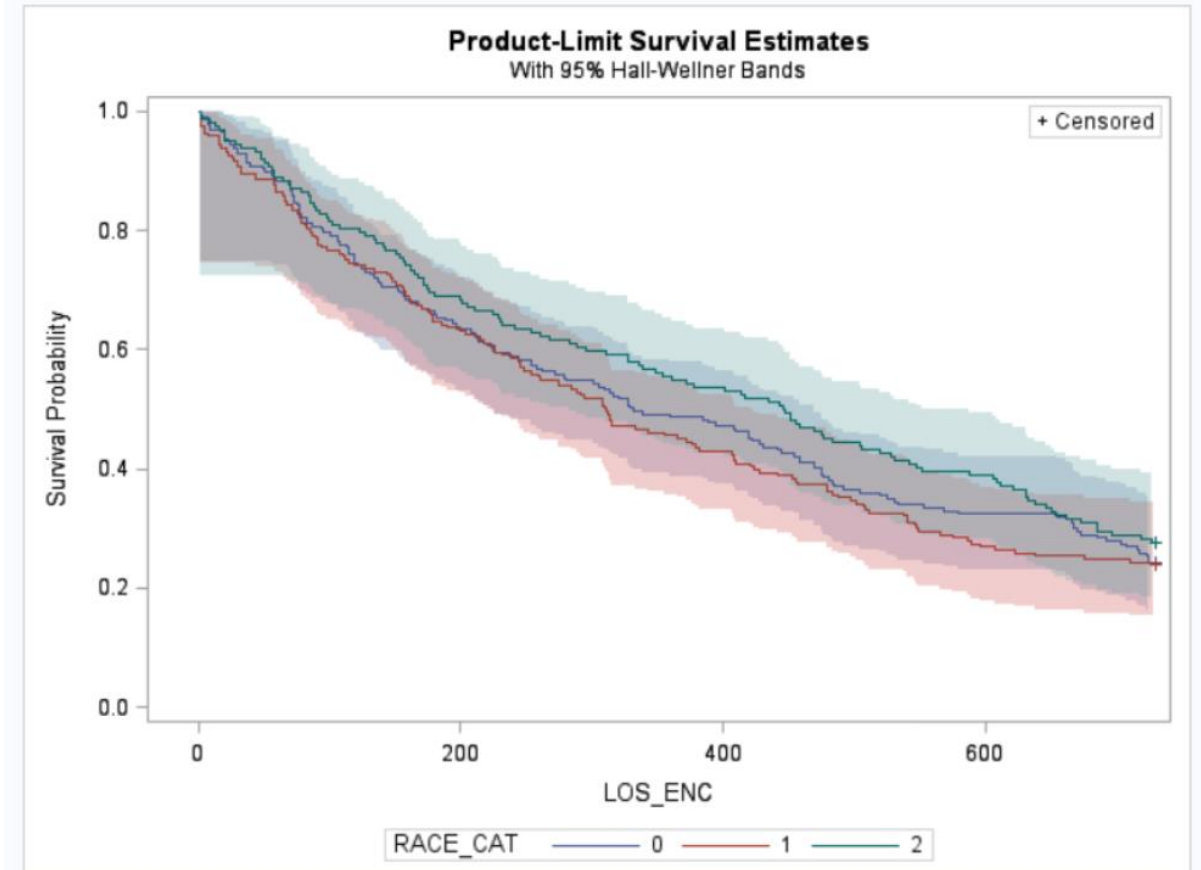




# Exploration of Factors Impacting Retention



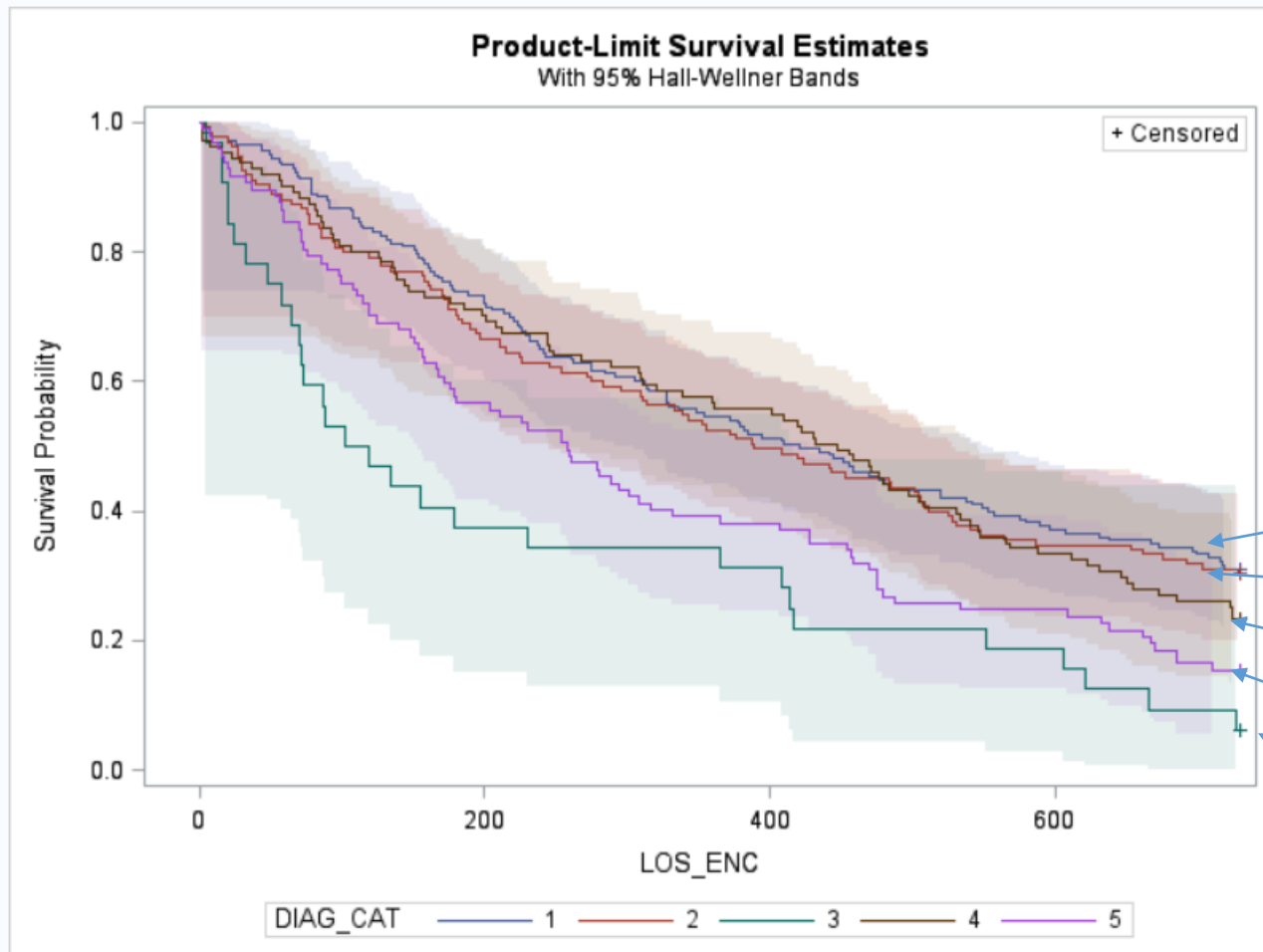
Gender: Blue: Female; Red: Male



Race/Ethnicity: Blue: White; Red: Black; Green: Hispanic



# Exploration of Factors Impacting Retention



Schizophrenia & Schizophreniform ( $n=183$ )

Schizoaffective Disorder ( $n=135$ )

Bipolar Disorder ( $n=111$ )

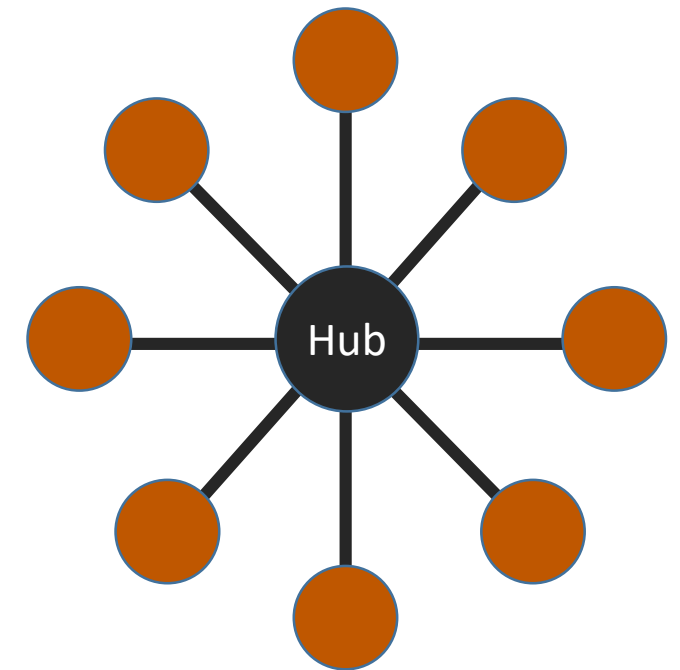
Major Depression ( $n=97$ )

Other Psychoses ( $n=32$ )



# Early Psychosis Intervention Network (EPINET)

- Concept outlined in 2015
- Regional networks of early psychosis programs – hub and spoke model
- Harmonization of measures – PhenX Toolkit
- Informatics tools to collect de-identified person-level data
- Promote measurement-based care
- Continuous improvement and innovation
- Practice-based research to drive scientific discovery
- Inclusive of pilot services research project





## 2019 EPINET Sites

- EPI-CAL (12 clinics in California)
- ESPIRITO (11 clinics in 4 states)
- LEAP (clinics in Massachusetts)
- OnTrackNY (21 clinics in New York)
- Targeting Cognition & Motivation (6 teams in Minnesota)
- EPINET National Data Coordinating Center

## Some Research Efforts

- Develop a measure of DUP
- Reducing DUP through outreach
- App to support treatment adherence
- Electronic treatment interventions to reduce disengagement
- Examine clinical heterogeneity and its impact on outcomes
- Develop a suicide prevention protocol
- Mobile intervention targeting cognition & motivation