

A MODEL ADDRESSING TRANSITION DISPARITIES FOR YOUNG WOMEN WITH CONGENITAL HEART DISEASE (CHD)

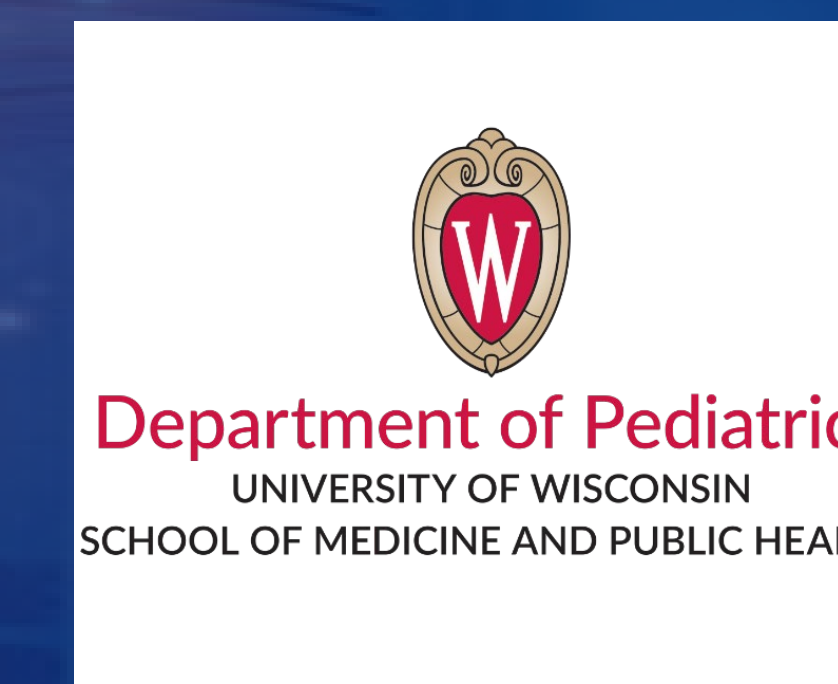
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Building Interdisciplinary Research Careers in Women's Health

BACKGROUND

Congenital heart disease now spans a life course

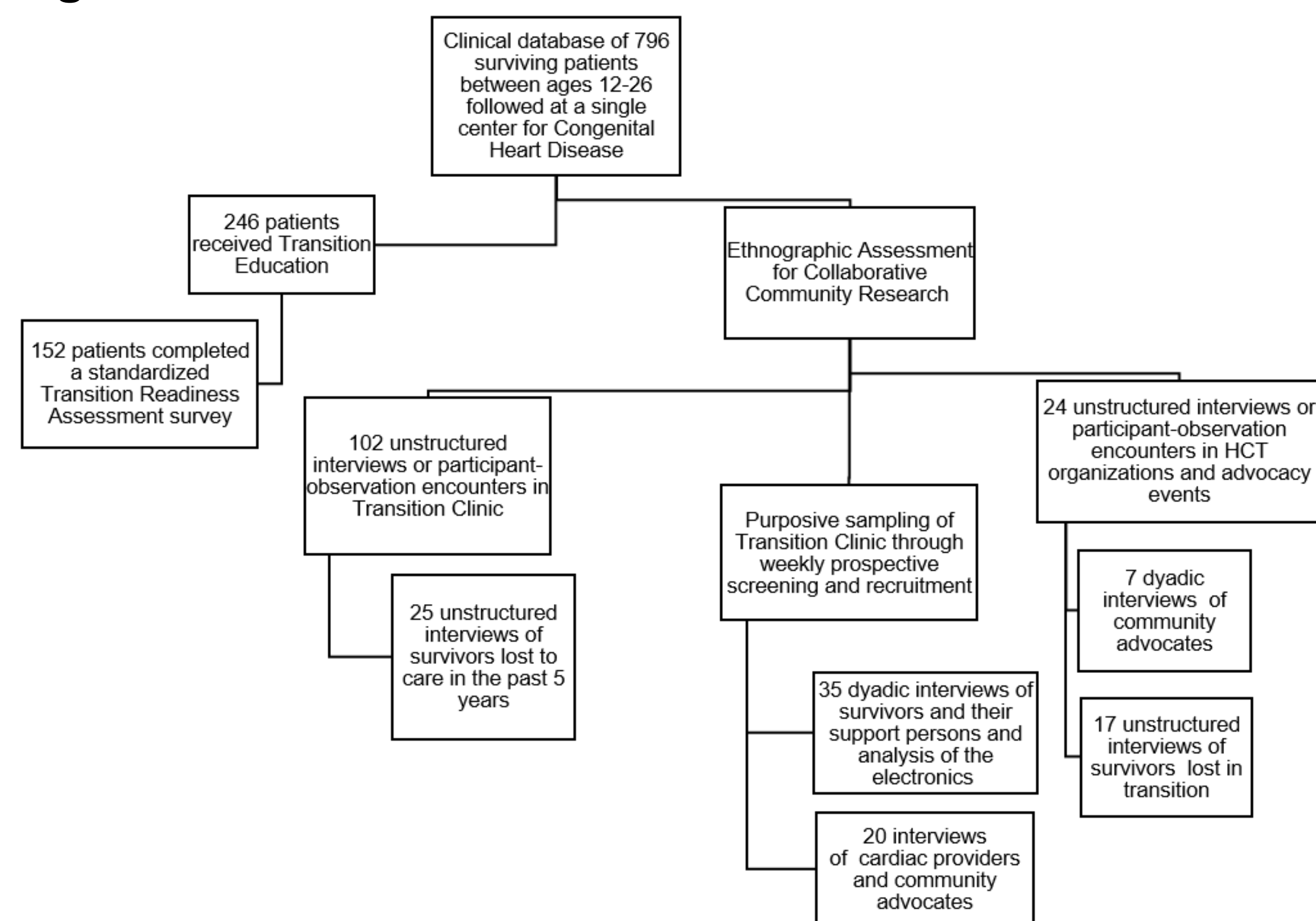
- Over half of patients are lost in the understudied transition from pediatric to adult care
- Women report worse quality of life over time

OBJECTIVES

- Observational, mixed methods, study of youth 12-26 with congenital heart disease
- Evaluate sex and gender differences in transition attitudes and experiences of young people, caregivers, healthcare providers and community advocates
- Co-design an accessible healthcare model

METHODS

Figure 1. Overview of ACHD STRONG



Mixed methods analysis of transition readiness assessments, electronic health records, observations, and interviews in a stratified sample of 796 patients from 2021-2024

RESULTS

Supplementary Table and Figure with Ethnographic Analysis of Sex and Gender [QR Code]



RESULTS

Reducing the burden of congenital heart disease transition, without addressing gender or disability, reinforces outcome disparities.

A community-informed model can improve accessibility.

Table 1: Sex Disparities in Transition Readiness by Disability Status

	Patients w/o disabilities in EHR (N=98)			Patients w/ disabilities in EHR (N=54)		
	Males (N=52)	Females (N=46)	P value	Males (N=31)	Females (N=23)	P value
Confidence in taking care of heart care*, mean (SD)	6.1 (3.1)	5.0 (3.7)	0.234	7.5 (2.5)	5.2 (3.7)	0.011
I know I need life-long heart care from a congenital heart disease specialist, N (%)	43 (93.5)	31 (73.8)	0.023	24 (88.9)	17 (77.3)	0.429
I know what to do in case I have a medical emergency, N (%)	39 (84.8)	37 (88.1)	0.651	26 (86.7)	13 (59.1)	0.023
I have a paper or electronic file for my medical information, N (%)	23 (51.1)	22 (52.4)	0.906	18 (60.0)	6 (27.3)	0.019
I carry important health information with me every day, N (%)	23 (51.1)	13 (31.0)	0.056	18 (60.0)	7 (31.8)	0.044

*Range 0-10, with a higher score representing more confidence. Bolded values represent significance at the 0.05 level.

Figure 2: Tracking Reinforces Hospital, School, and Service Silos

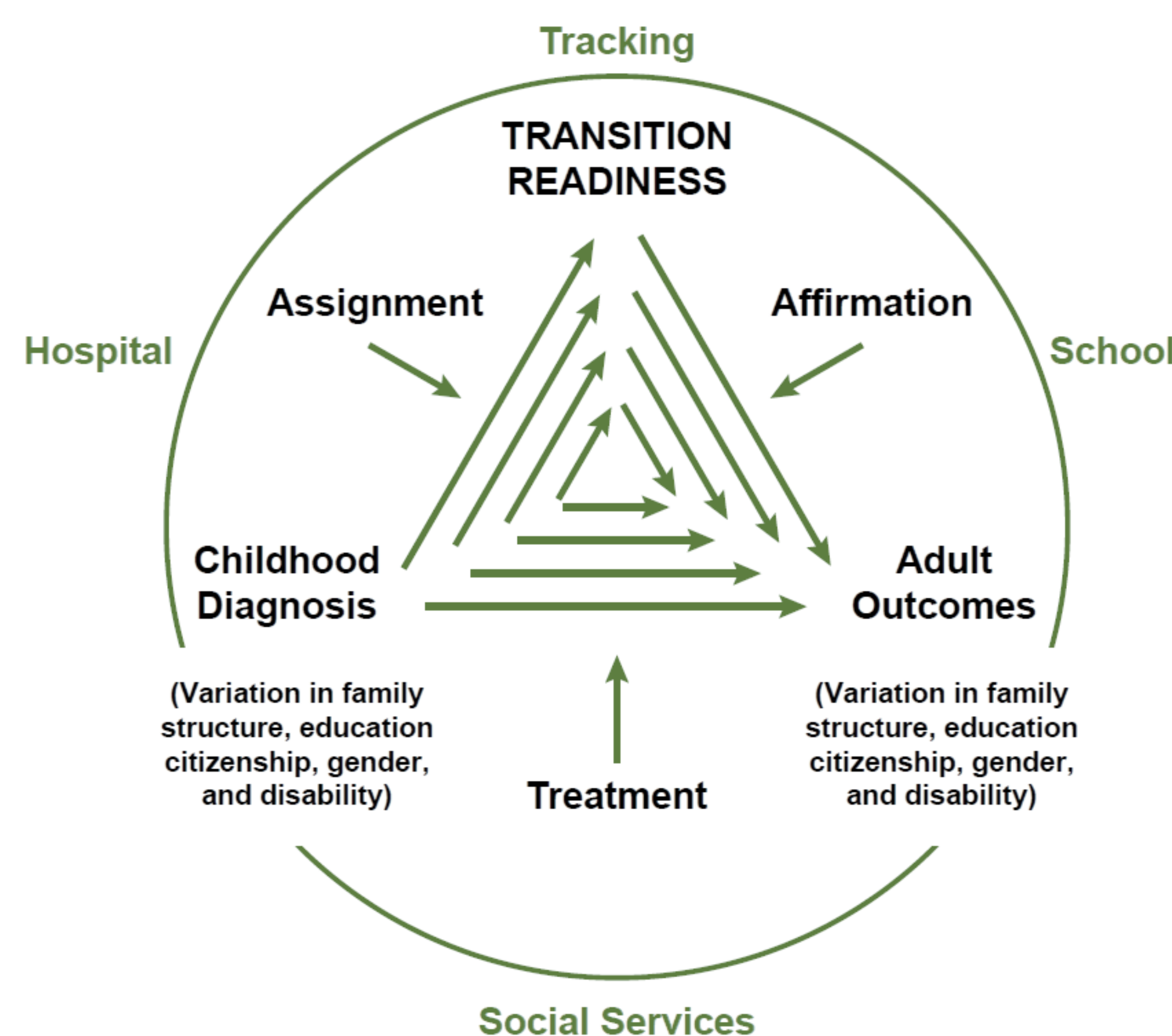
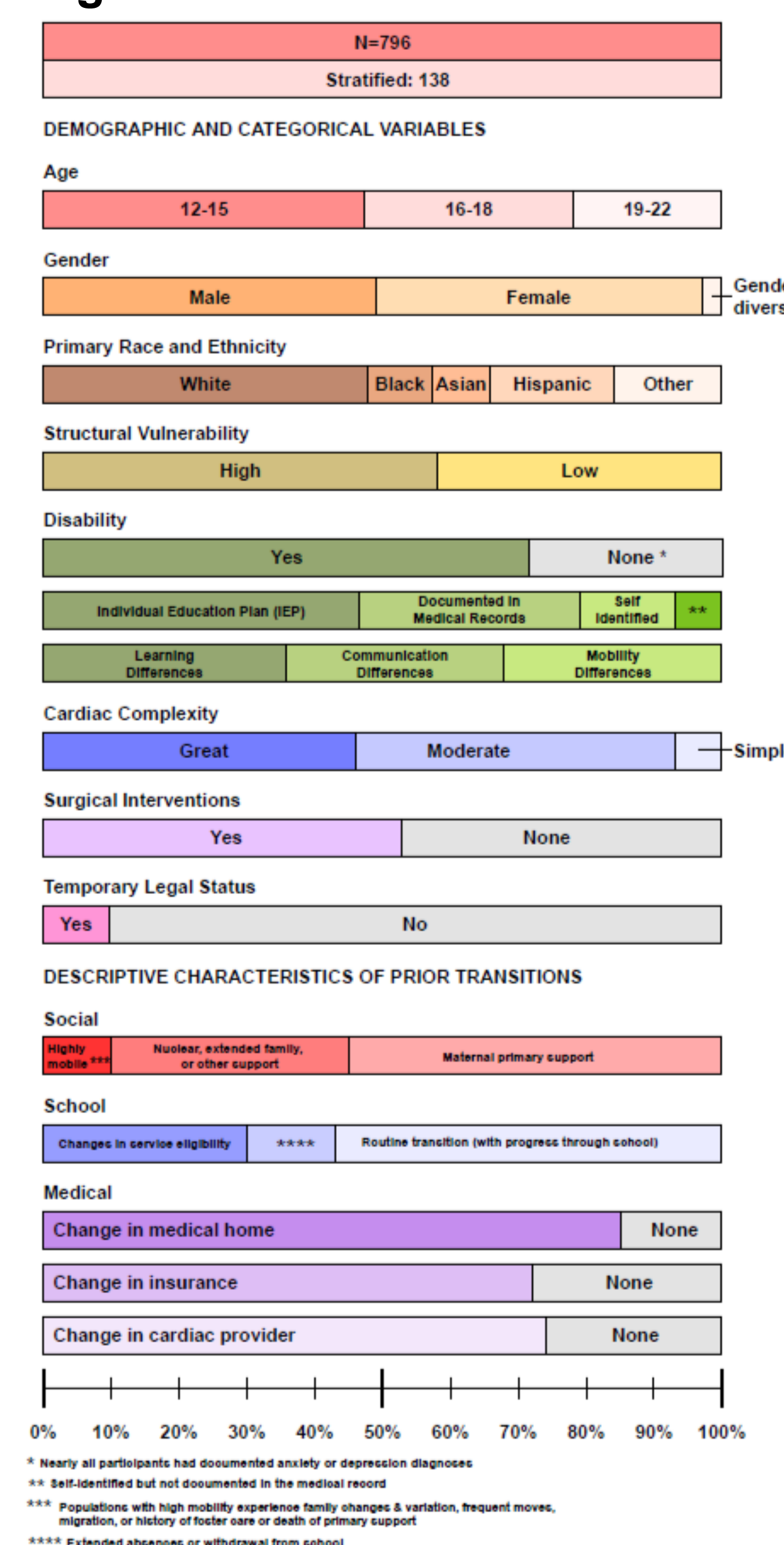


Figure 3: Stratified CHD Patients



DISCUSSION

Life-stage models used in transition interventions may reinforce tracking by hospitals, schools, and social services (Table 1). Tracking occurs when youth are grouped by actual or assumed developmental differences or needs (Figure 2). Tracking benefits, controls, and intensifies structural advantage and disadvantage among patients (QR Code, Table 2) through three mechanisms:

- 1. Affirmation:** Reinforces patient identity; hyper-independence among young men
- 2. Assignment:** Gendered tasking of and by families, healthcare teams, and community advocates
- 3. Treatment:** Inaccessibility of health services across hospitals, school, and communities, particularly reproductive healthcare

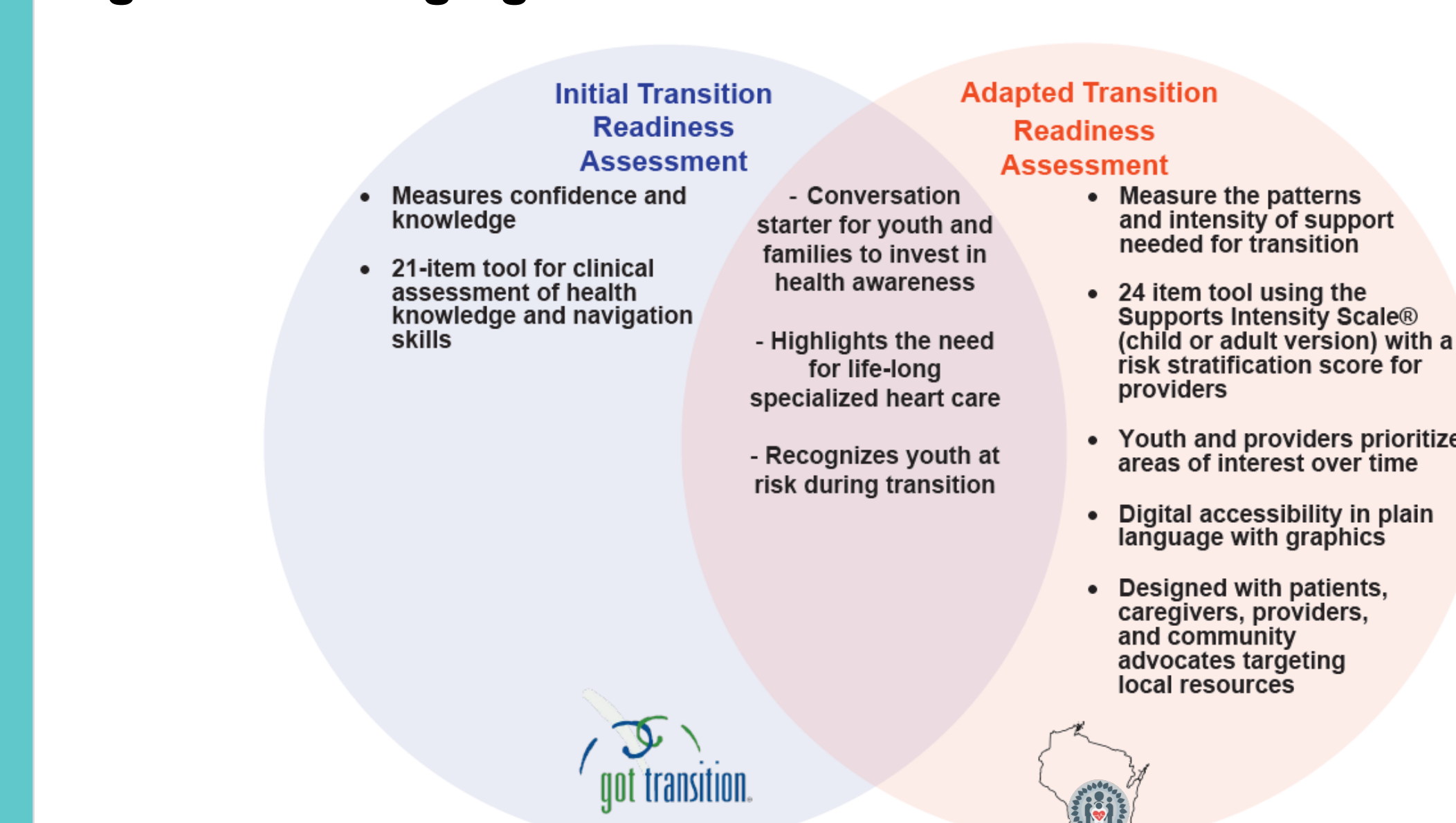
Changing what we measure (Figure 4) and shifting from shared decision-making in childhood to supported decision-making in adulthood may disrupt tracking practices that increase risk of patients becoming lost in the transition (QR Code, Figure 5).

LIMITATIONS

- Our prior research shows that 92% of patients report a mother led care network where mothers, stepmother, grandmother, or an adoptive mother was most prominent 76% of time which may not reflect variations across healthcare settings and regions
- Structured interviews were dyadic and therefore limited by power dynamics between parents and adolescents. We addressed this limitation with unstructured interviews, and observations of clinical and community encounters

CONCLUSION

Figure 4: Changing What We Measure



FUNDING DECLARATION AND CONTACT

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