

BACKGROUND

- Patients with congenital heart diseases (CHD) are at greater risk of incurring medical complications and neurocognitive deficits, but advancements in medical care have allowed greater quality of life and life expectancy^{1, 2}
- There are known factors associated with gaps in care, such as via patients not knowing the need for follow-up care, insurance issues, and reluctance to develop new physician relationships.³
- Transitional care may lower the risk of loss to follow-up and poor outcomes in patients via consistent early interventions, but transitional care has not yet been standardized.

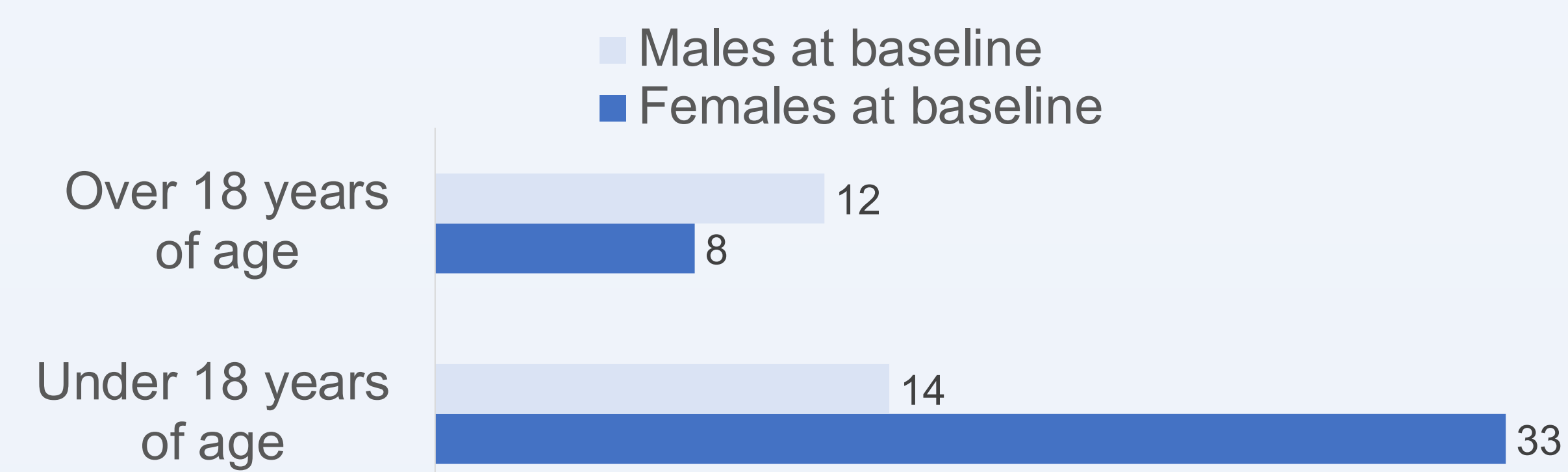
OBJECTIVES

- (1) To identify individual barriers for a successful transition;
- (2) To improve knowledge and education about cardiac conditions and importance of transition;
- (3) To establish a pathway to create effective goals for patients and their families regarding tasks needed for successful transition.

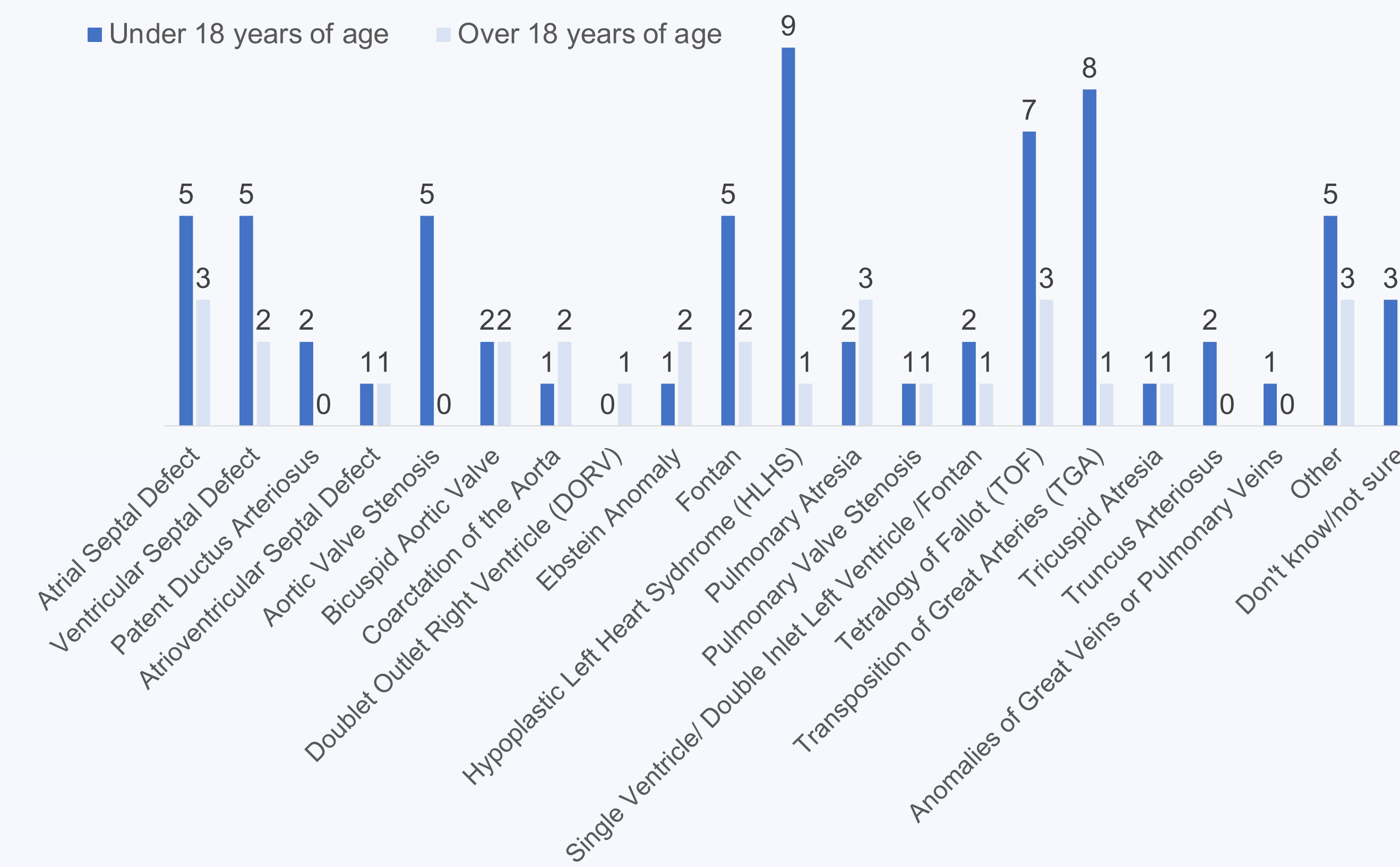
EDUCATIONAL GOALS AND TOPICS

- | <u>Medical Knowledge</u> | <u>Care Coordination</u> | <u>Mental Health</u> |
|---|--|---|
| <ul style="list-style-type: none"> • Understanding my diagnosis • Building a portable medical summary • Why are my medications important? • Endocarditis • Warfarin • Pacemaker Care • Exercise and ACHD | <ul style="list-style-type: none"> • Advance directives • Obtaining and using health insurance • Working with your doctor during your visit • Requesting medication refills • How to find an adult doctor | <ul style="list-style-type: none"> • How to find a therapist • Stress and anxiety explained • PTSD • Mindfulness-based stress reduction |

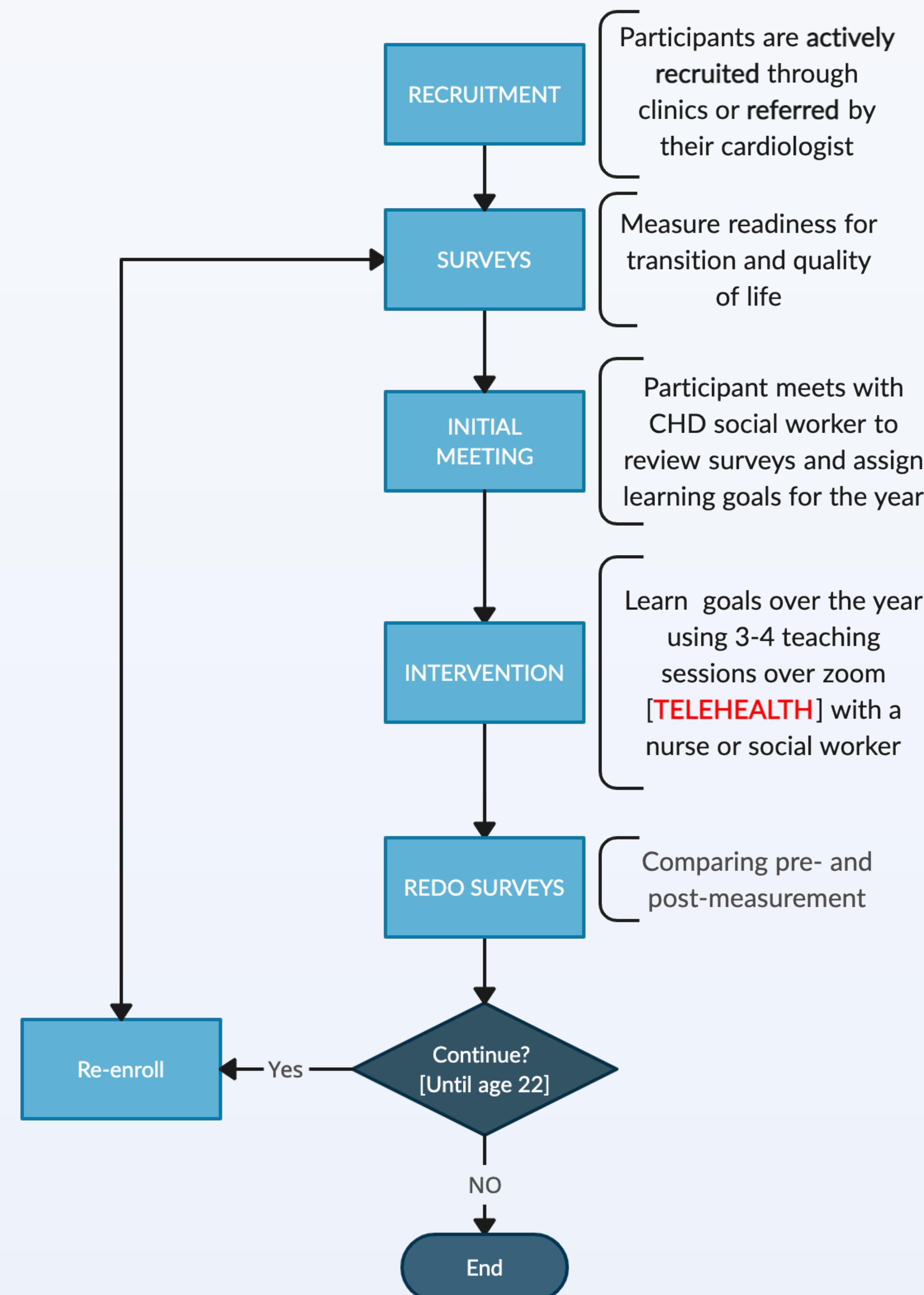
PARTICIPANT DEMOGRAPHICS



PARTICIPANT-REPORTED HEART DISEASE DEMOGRAPHICS



METHODS



RESULTS

	Participants < 18 years old			Participants > 18 years old		
	Yes, I know this	I need to learn more	Not Applicable	Yes, I know this	I need to learn more	Not Applicable
I can name and/or describe my heart condition	51.1%	45.8%	2.1%	40.0%	60.0%	0.0%
I can name and/or describe the cardiac surgeries or procedures that I have had	29.8%	61.7%	8.5%	35.0%	65.0%	0.0%
I take part in making choices about my healthcare	51.1%	48.9%		51.1%	48.9%	
I know what Cardiac Symptoms Require more Urgent Medical Attention	31.9%	66.0%	2.1%	45.0%	40.0%	15.0%

	Participants < 18 years old		Participants > 18 years old	
	Yes, I know this	I need to learn more	Yes, I know this	I need to learn more
I make my own medical appointments			45.0%	55.0%
I know how to refill my medications	27.7%	72.3%	27.7%	72.3%
I know how to contact my health insurance company with questions or concerns	10.6%	89.4%	15.0%	85%

	Participants < 18 years old				
	Never	Almost Never	Sometimes	Often	Almost Always
I worried about what could happen to me	70.2%	10.6%	10.6%	6.4%	2.1%
I could not stop feeling sad	76.6%	17.0%	4.3%	2.1%	0.0%
I felt lonely	78.7%	8.5%	10.6%	2.1%	0.0%
It was hard for me to have fun	66.0%	17.0%	14.9%	2.1%	0.0%
	Participants > 18 years old				
	Never	Almost Never	Sometimes	Often	Almost Always
My worries overwhelmed me	47.4%	5.3%	15.8%	21.1%	10.5%
I felt depressed	52.6%	10.5%	10.5%	21.1%	5.3%

DISCUSSION

- Most participants (under 18 and over 18 years old) do not report adequate care coordination skills, such as the ability to refill medication or correspond with their health insurance companies.
- Participants over the age of 18 years more often report feelings of depression and worries than participants under 18 years of age, possibly indicating a larger mental burden on CHD patients as they age.
- A large percentage of patients have not yet achieved an adequate level of transition readiness.

CONCLUSIONS AND FUTURE DIRECTIONS

- This mode of transitional care offers participants in the program the opportunity to address specific goals through a telehealth format.
- This intervention has identified gaps pertaining to medical knowledge, care coordination, and mental health at baseline
- Long-term research is necessary to address the efficacy of this transitional care model and its impact on medical outcomes.

REFERENCES

1. Howell, Heather B et al. "Neurodevelopmental outcomes of children with congenital heart disease: A review." *Current problems in pediatric and adolescent health care* vol. 49,10 (2019): 100685. doi: 10.1016/j.cppeds.2019.100685
2. Scott, Michael, and Ashley E Neal. "Congenital Heart Disease." *Primary care* vol. 48,3 (2021): 351-366. doi: 10.1016/j.pop.2021.04.005
3. Goossens, Eva et al. "Are missed appointments in an outpatient clinic for adults with congenital heart disease the harbinger for care gaps?" *European journal of cardiovascular nursing* vol. 21,2 (2022): 127-134. doi:10.1093/eurjcn/zvab012