

# Taking ACTION on Outcomes that Matter Most to You

## Patient and Parent Reported Outcomes (PROs)

### What are PROs?

Patient reported outcomes (PROs) are measures of health, symptoms, behavior, or experiences as reported by a patient or parent. PROs provide helpful information allowing us to improve care provided. Your heart team may think they know what matters most to you, but the best way to really know is to ask you! This is why ACTION and your heart team have teamed up to collect your PROs. We will ask about your physical and emotional health, as well as how your family is coping.



### Who completes ACTION PROs?

- If the patient is:
  - ♥ **under 12 years old:** a parent is asked to complete PROs
  - ♥ **12–17 years old:** a patient can complete their own PROs, and/or a parent can also complete a separate PRO
  - ♥ **18 years or older:** just the patient will complete PROs

### How do you complete them?

- You can complete PROs by **text or email**.

### How often do you complete them? And how long does it take?

- About **10– 20 minutes**
- PROs need to be completed:
  - ♥ **Pre-VAD Surgery & Weekly for the 1st Month**
  - ♥ **After VAD Surgery Months 1, 3, 6**

**My username:** \_\_\_\_\_

**My password:** \_\_\_\_\_

*Note: If you get locked out of your account, contact your care team for assistance.*

### What will your heart care team and ACTION do with the PROs?

We are currently testing this out. We want to see if PROs can be easily completed without causing an extra burden for patients, families and heart teams. Your heart team will be encouraged to look at the PROs. This is a new process. We are still learning the best way to use it, therefore any and all concerns should be discussed with your heart team.

After completing this testing phase, we will work together across ACTION centers to develop ways to best help patients and families based on what we have learned from the PROs collected.

