

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.



Scan to enroll.

How do I enroll in the MyDataHelps™ platform?

Click the link or scan the QR code to enroll.

<https://mydatahelps.org/e/KVWSML>

Username: _____

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

Who completes ACTION PROs?

Once you are consented for ACTION, you can be enrolled in PRO's. There are **different options for enrollment based on patient age and VAD implant date**. Your provider will help you enroll in the platform. If a patient is **under 18 years** of age, surveys will be sent to a caregiver.

How do you complete them?

You will be sent reminder notifications to complete the PROs. Click on the link in the text or email to complete the PROs, or you can log into your MyDataHelps (MDH) account either online at <https://mydatahelps.org/> or in the mobile app.

How long does it take?

Average of **5 minutes or less** per survey completion

How often is it needed?

PROs need to be completed:

- ♥ Pre-VAD Surgery & Weekly for the 1st Month
- ♥ After VAD Surgery Months 1, 3, 6

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.

