

APPENDIX D: ACTION Patient-Reported Outcome Pilot Measures and Timeline

Patient age (years)	Measure	Timeline for measures from VAD implant onward				
		VAD Implant	Weekly	1 month	3 months	6 months
0-1	Take ACTION*	X	X	X	X	X
2-4	Take ACTION*	X	X	X	X	X
	VAS	X	X	X	X	X
5-7	Take ACTION*	X	X	X	X	X
	VAS	X	X	X	X	X
	PROMIS-25 parent proxy	X		X	X	X
8-17	Take ACTION*	X	X	X	X	X
	VAS	X	X	X	X	X
	PROMIS-25 parent proxy	X		X	X	X
≥18	Take ACTION^	X	X	X	X	X
	VAS	X	X	X	X	X
	PROMIS-29 self-report	X		X	X	X

Take ACTION = Take ACTION checklist parent report* or self-report^; VAS = visual analog scale, quality of life; PROMIS-25 parent proxy = PROMIS Parent Proxy-25 Profile v2.0; PROMIS-29 self-report = PROMIS-29 Profile v2.1