

## **APPENDIX A: Patient and Family Survey**

1. I am a:

- a) Patient
- b) Mother
- c) Father

2. Age of the child of VAD \_\_\_\_\_

Today I am/my child is:

- a) Inpatient in ICU
- b) Inpatient on WARD
- c) Outpatient

3. What makes a day "good" for you and/or your child?

4. What makes a day "bad"?

5. What do you wish people would know about living with a VAD?

6. Circle any symptoms that you think clinicians should ask you about:

- |                  |                     |
|------------------|---------------------|
| Fatigue          | Noise of the VAD    |
| Pain             | Alarms              |
| Loss of appetite | Bleeding            |
| Vomiting         | Blood draws         |
| Dizziness        | Nervousness         |
| Worry            | Sadness             |
| Boredom          | Belly pain          |
| Sleep            | Head ache           |
| Irritability     | Shortness of breath |
| Constipation     | Diarrhea            |
| Thirst           | Sweating            |