

SUPPLEMENTAL TABLE S1. FONTAN REFERRAL SURVEY QUESTIONS

SURVEY PART 1

Email of the individual to receive 30-day followup email	
ACTION patient ID	
Form Start Timestamp	
Date of referral (not consultation)? if known	
Date of consultation?	
Did the initial consultation occur as an inpatient or outpatient?	1, Inpatient 2, Outpatient
	0.5, 0.5 1, 1 1.5, 1.5 2, 2 2.5, 2.5 3, 3 3.5, 3.5 4, 4 4.5, 4.5 5, 5 5.5, 5.5 6, 6 6.5, 6.5 7, 7 7.5, 7.5 8, 8 8.5, 8.5 9, 9 9.5, 9.5 10, 10 10.5, 10.5 11, 11 11.5, 11.5 12, 12 12.5, 12.5 13, 13 13.5, 13.5 14, 14 14.5, 14.5 15, 15 15.5, 15.5 16, 16 16.5, 16.5 17, 17 17.5, 17.5 18, 18 18.5, 18.5 19, 19 19.5, 19.5 20, 20 20.5, 20.5 21, 21 21.5, 21.5 22, 22 22.5, 22.5 23, 23 23.5, 23.5 24, 24 24.5, 24.5 25, 25 25.5, 25.5 26, 26 26.5, 26.5 27, 27 27.5, 27.5 28, 28 28.5, 28.5 29, 29 29.5, 29.5 30, 30 30.5, 30.5 31, 31 31.5, 31.5 32, 32 32.5, 32.5 33, 33 33.5, 33.5 34, 34 34.5, 34.5 35, 35 35.5, 35.5 36, 36 36.5, 36.5 37, 37 37.5, 37.5 38, 38 38.5, 38.5 39, 39 39.5, 39.5 40, 40 42, >40
Age at consultation (in 0.5 years)	
Sex	1, Male 2, Female
	0.5, 0.5 1, 1 1.5, 1.5 2, 2 2.5, 2.5 3, 3 3.5, 3.5 4, 4 4.5, 4.5 5, 5 5.5, 5.5 6, 6 6.5, 6.5 7, 7 7.5, 7.5 8, 8 8.5, 8.5 9, 9 9.5, 9.5 10, 10 10.5, 10.5 11, 11 11.5, 11.5 12, 12 12.5, 12.5 13, 13 13.5, 13.5 14, 14 14.5, 14.5 15, 15 15.5, 15.5 16, 16 16.5, 16.5 17, 17 17.5, 17.5 18, 18 18.5, 18.5 19, 19 19.5, 19.5 20, 20 20.5, 20.5 21, 21 21.5, 21.5 22, 22 22.5, 22.5 23, 23 23.5, 23.5 24, 24 24.5, 24.5 25, 25 25.5, 25.5 26, 26 26.5, 26.5 27, 27 27.5, 27.5 28, 28 28.5, 28.5 29, 29 29.5, 29.5 30, 30 30.5, 30.5 31, 31 31.5, 31.5 32, 32 32.5, 32.5 33, 33 33.5, 33.5 34, 34 34.5, 34.5 35, 35 35.5, 35.5 36, 36 36.5, 36.5 37, 37 37.5, 37.5 38, 38 38.5, 38.5 39, 39 39.5, 39.5 40, 40 42, >40
Age at Fontan (in 0.5 years)	
Is the patient's primary cardiologist employed at the HF consultation center?	1, Yes 0, No
Is the patient's primary cardiologist from a Fontan multidisciplinary clinic?	
Is the patient's primary cardiologist a HF cardiologist?	1, Yes 0, No
Was a reason for referral specified	1, Yes 0, No
If yes, what was it (free text)	
Last assessment of systemic ventricle systolic function prior to referral:	1, Echo 2, MRI 3, Cath
For Echo, systemic ventricle systolic function:	1, Normal 2, Mildly depressed 3, Mild-mod 4, mod 5, mod-severe 6, Severe
For MRI, systemic ventricle systolic function:	1, Normal 2, Mildly depressed 3, Mild-mod 4, mod 5, mod-severe 6, Severe
For Cath, systemic ventricle systolic function:	1, Normal 2, Mildly depressed 3, Mild-mod 4, Mod 5, Mod-severe 6, Severe
Last assessment of AV-Valve regurgitation prior to referral:	1, Echo 2, MRI 3, Cath
For Echo, AV-Valve regurgitation:	1, Normal 2, Mild 3, Mild-mod 4, Mod 5, Mod-severe 6, Severe 7, None
For MRI, AV-Valve regurgitation:	1, Normal 2, Mild 3, Mild-mod 4, Mod 5, Mod-severe 6, Severe 7, None
For Cath, AV-Valve regurgitation:	1, Normal 2, Mild 3, Mild-mod 4, mod 5, mod-severe 6, Severe 7, None
Patient weight at consultation (kg)	
Patient height at consultation (cm)	
Did the patient have an exercise test within the last 6 months	1, Yes 0, No
If yes - max VO2 (number) mL/kg/min	
Did the patient have a 6 minute walk within the last 6 months	1, Yes 0, No
If yes - distance walked	
If yes, lowest O2 saturation	
Did the patient report exercise intolerance at consultation visit	1, Yes 0, No
Does the patient have a pacemaker	1, Yes 0, No
Does the patient have an ICD	1, Yes 0, No
History of arrhythmia in the last year prior to referral	1, Yes 0, No
Is the patient receiving medical therapy for arrhythmia	1, Yes 0, No
Is the patient on inotrope infusion at the time of consultation	1, Yes 0, No
Did the patient have chronic/recurrent ascites	1, Yes 0, No
Did the patient have chronic/recurrent pleural effusions	1, Yes 0, No
Has the patient been hospitalized in the year leading up to referral for ascites/pleu	1, Yes 0, No
How many times has he/she been admitted in the last year?	1, 1 2, 2 3, 3 4, 4 5, 5 6, 6 7, 7 8, 8 9, 9 10, 10 11, >10
Has the patient had new or increased diuretic therapy in the year leading up to refe	1, Yes 0, No
Has the patient had a cath in the last 2 years	1, Yes 0, No
VEDP	
most representative Fontan pressure	
Cardiac Index	
systemic saturation (%)	
NYHA class	1, 1 2, 2 3, 3 4, 4
Does the patient have clinically significant PLE or is the patient receiving chronic the	1, Yes 0, No
Does the patient receive chronic albumin infusions	1, Yes 0, No
# of admissions for PLE in 12 months prior to referral	
Does the patient have clinically significant plastic bronchitis or is the patient receivir	1, Yes 0, No
Has the patient had hemoptysis requiring urgent medical evaluation	1, Yes 0, No
Does the patient have imaging evidence of liver fibrosis	1, Yes 0, No

Does the patient have synthetic liver dysfunction in his or her baseline state?

1, Yes | 0, No

If yes - specify the laboratory abnormality noted

Serum bilirubin at consultation

Serum Cr at consultation

Serum cystatin C at referral

Serum BUN at referral

How long did it take you to fill out this form

SURVEY PART 2

Outcome of Consultation Visit Form Start Timestamp

1, Referral back to primary cardiologist, no future visits scheduled at HF center | 2, Suggestion to co-manage with primary cardiologist | 3, Assumed care of patient at HF center | 4, Referral for cardiac catheterization | 5, Initiated heart transplant listing evaluation within 30 days | 6, Initiated heart-liver transplant evaluation within 30 days | 7, Initiated heart-kidney transplant evaluation within 30 days | 8, Initiated VAD evaluation within 30 days | 9, Initiated inotropes within 30 days | 10, Referral for surgical Fontan revision within 30 days | 11, Referral for other cardiac surgery within 30 days | 12, Referral for ICD within 30 days | 13, Referral for pacemaker within 30 days | 14, Referral for lymphatic intervention | 99, Other

Outcome of consultation visit: (not mutually exclusive - check all that apply):

Other Referral?

If referral for specific interventional cardiac catheterization, did the intervention occur? 1, Yes | 0, No

If evaluated for transplant listing - was patient listed

1, Yes | 0, No

If N, why not

1, Too sick | 2, Too well | 3, Alternative therapy sought | 4, Patient choice

If VAD evaluation - was VAD placed

1, Yes | 0, No

If Y - device type

1, HeartMate 3 | 2, HeartWare HVAD | 3, Berlin Heart | 4, SynCardia TAH | 5, Centrimag | 6, Pedimag | 7, Other

Please specify others

If N - why not

1, Too sick | 2, Unacceptable surgical risk | 3, Too well | 4, Alternative therapy sought | 5, Patient choice | 6, Anatomically not a candidate | 7, Physiologically not a candidate

If surgical Fontan revision, did surgery occur

1, Yes | 0, No

If other cardiac surgery, did surgery occur

1, Yes | 0, No

If ICD referral, was ICD placed

1, Yes | 0, No

If pacemaker referral, was pacemaker placed

1, Yes | 0, No

How long did it take you to fill out this form