

**Section A: KEY IDENTIFYING INFORMATION**

A1. Study Identification Number \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

Replaced by blinded subject ID

blind_id	Blinded ID
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A2. Acrostic Identifier \_\_\_\_\_  
Removed to protect privacy

A3. Study visit STUDY VISIT 3 (12 months)..... 3

A4. Date of form completion \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
M M / D D / Y Y Y Y

Replaced by age at date start inclusion/exclusion screening, days

R105_age	<created var>Age at date of form completion, days
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A5. Name of person completing form \_\_\_\_\_  
PRINT FULL NAME INITIALS

Removed to protect privacy

**Section B: POST-STAGE II MEDICAL and SURGICAL HISTORY**

B1. Number of interventional cardiac catheterizations \_\_\_\_\_ (0-5) (If 0, skip to B2)  
[DO NOT list diagnostic catheterizations]

Cardiac Catheterization Intervention Code (See Code List F) [code required for data entry]						6. Date of Interventional Cardiac Catheterization
1. Level 1	2. Level 2	3. Level 3	4. Level 4	5. Level 5		
a. _____ - _____ - _____ - _____ - _____						_____ / _____ / _____ M M / D D / Y Y Y Y
						Name of intervention
b. _____ - _____ - _____ - _____ - _____						_____ / _____ / _____ M M / D D / Y Y Y Y
						Name of intervention

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(Not All Dataset Variables are Shown)

c.	_____ - _____ - _____ - _____ - _____	<table border="1"> <tr> <td>__</td><td>__</td><td>/</td><td>__</td><td>__</td><td>/</td><td>__</td><td>__</td><td>__</td><td>__</td> </tr> <tr> <td>M</td><td>M</td><td></td><td>D</td><td>D</td><td></td><td>Y</td><td>Y</td><td>Y</td><td>Y</td> </tr> </table>	__	__	/	__	__	/	__	__	__	__	M	M		D	D		Y	Y	Y	Y
		__	__	/	__	__	/	__	__	__	__											
M	M		D	D		Y	Y	Y	Y													
		Name of intervention																				

CATHNO	B1. Number of interventional cardiac catheterizations
cathcod	<created var> Concatenation of all catheterization codes
cath0	B1a.<created var>Pre-stg2 interventional catheterization
cath_age_0	B1a <created var> Age at date of interventional cardiac catheterization, days
CATHNAM_0	B1a.Pre-stg2 interventional catheterization name
cath1	B1b.<created var>Pre-stg2 interventional catheterization
cath_age_1	B1b <created var> Age at date of interventional cardiac catheterization, days
CATHNAM_1	B1b.Pre-stg2 interventional catheterization name
cath2	B1c.<created var>Pre-stg2 interventional catheterization
cath_age_2	B1c <created var> Age at date of interventional cardiac catheterization, days
CATHNAM_2	B1c.Pre-stg2 interventional catheterization name
cath3	B1d.<created var>Pre-stg2 interventional catheterization
cath_age_3	B1d <created var> Age at date of interventional cardiac catheterization, days
CATHNAM_3	B1d.Pre-stg2 interventional catheterization name
cath4	B1e.<created var>Pre-stg2 interventional catheterization
cath_age_4	B1e <created var> Age at date of interventional cardiac catheterization, days
CATHNAM_4	B1e.Pre-stg2 interventional catheterization name

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B2. Number of other surgical interventions \_\_\_\_\_ (0-5) (If 0, skip to **B5**)  
[DO NOT include stage II procedure or catheterization procedures listed previously]

Other Surgical Procedures			
Code	Procedure Name	Code	Procedure Name
01	Bowel surgery	13	Pulmonary artery reconstruction
04	Coarctation repair	16	Stage II revision
		17	Thoroцентesis
06	Diaphragm plication	18	Thoracic duct ligation
07	Extracorporeal membrane oxygenation	19	Thoracostomy tube
08	Gastrostomy tube	20	Thrombectomy
09	Pacemaker insertion*	21	Tracheostomy
10	Pericardial window	22	Transplantation
11	Pleurodesis	23	Ventriculostomy/VP shunt
		99	Other surgical procedure

\*If code 09 is selected, question B3 must be YES

**Surgical Code (See codes above)**

- a. \_\_\_\_\_ 1. If Other (99), specify: \_\_\_\_\_
- b. \_\_\_\_\_ 1. If Other (99), specify: \_\_\_\_\_
- c. \_\_\_\_\_ 1. If Other (99), specify: \_\_\_\_\_
- d. \_\_\_\_\_ 1. If Other (99), specify: \_\_\_\_\_
- e. \_\_\_\_\_ 1. If Other (99), specify: \_\_\_\_\_

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NUMSURG	B2. Number of other surgical interventions
surgcode	<created var> All other surgical interventions
SURGCOD_0	B2a.Other surgical interventions
SURG_S_0	B2a.Other surgical interventions,if other '99' specify
SURGCOD_1	B2b.Other surgical interventions
SURG_S_1	B2b.Other surgical interventions,if other '99' specify
SURGCOD_2	B2c.Other surgical interventions
SURG_S_2	B2c.Other surgical interventions,if other '99' specify
SURGCOD_3	B2d.Other surgical interventions
SURG_S_3	B2d.Other surgical interventions,if other '99' specify
SURGCOD_4	B2e.Other surgical interventions
SURG_S_4	B2e.Other surgical interventions,if other '99' specify
SURGCOD_5	B2f.Other surgical interventions
SURG_S_5	B2f.Other surgical interventions,if other '99' specify

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B3. Number of above procedures for which patient was \_\_\_\_\_ (0 – 5) (If 0, skip to B4)  
placed on cardiopulmonary bypass.

	a. Procedure code (see Other Surgical Procedure codes above)	b. Bypass minutes	c. DHCA Yes= 1 No = 2	d. DHCA minutes	e. RCP Yes= 1 No = 2	f. RCP minutes	g. RCP flow cc/kg/min	h. Lowest temp. °C during bypass, regardless of location	i. HCT %
1.	___	_____	___	_____	___	_____	_____	____.____	____.____
If "other" procedure, specify: _____									
2.	___	_____	___	_____	___	_____	_____	____.____	____.____
If "other" procedure, specify: _____									
3.	___	_____	___	_____	___	_____	_____	____.____	____.____
If "other" procedure, specify: _____									
4.	___	_____	___	_____	___	_____	_____	____.____	____.____
If "other" procedure, specify: _____									
5.	___	_____	___	_____	___	_____	_____	____.____	____.____
If "other" procedure, specify: _____									

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CPB	[Added version B] B3. Number of above procedures for which patient was placed on cardiopulmonary bypass.
CPB_EV_0	[Added version B] B3.1.a. Procedure code
CPB_MN_0	[Added version B] B3.1.b. Bypass minutes
CPB_SPC_0	[Added version B] B3.1.1a. Specify 'other' procedure code
DHCA_MN_0	[Added version B] B3.1.d. DHCA time, minutes
DHCA_YN_0	[Added version B] B3.1.c. On DHCA
HCT_PCT_0	[Added version B] B3.1.i. HCT, percent
LOW_TEMP_0	[Added version B] B3.1.h. Lowest temperature during bypass, Celsius
RCPFLOW_0	[Added version B] B3.1.g. RCP flow, cc/kg/min
RCP_MN_0	[Added version B] B3.1.f. RCP time, minutes
RCP_YN_0	[Added version B] B3.1.e. On RCP
CPB_EV_1	[Added version B] B3.2.a. Procedure code
CPB_MN_1	[Added version B] B3.2.b. Bypass minutes
CPB_SPC_1	[Added version B] B3.2.1a. Specify 'other' procedure code
DHCA_MN_1	[Added version B] B3.2.d. DHCA time, minutes
DHCA_YN_1	[Added version B] B3.2.c. On DHCA
HCT_PCT_1	[Added version B] B3.2.i. HCT, percent
LOW_TEMP_1	[Added version B] B3.2.h. Lowest temperature during bypass, Celsius
RCPFLOW_1	[Added version B] B3.2.g. RCP flow, cc/kg/min
RCP_MN_1	[Added version B] B3.2.f. RCP time, minutes
RCP_YN_1	[Added version B] B3.2.e. On RCP

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B4. Permanent pacemaker placed? YES .....1 NO .....2 **(B5)**

a. Date of placement  $\frac{\text{M}}{\text{M}} / \frac{\text{D}}{\text{D}} / \frac{\text{Y}}{\text{Y}} \frac{\text{Y}}{\text{Y}} \frac{\text{Y}}{\text{Y}}$

b. Type of pacemaker PERMANENT EPICARDIAL ATRIAL PACING .....1  
 PERMANENT EPICARDIAL VENTRICULAR PACING.....2  
 PERMANENT EPICARDIAL DUAL CHAMBER PACING.....3  
 OTHER.....99

1. OTHER, specify \_\_\_\_\_

PACER	B4. Permanent pacemaker placed?
pacер_age	B4a <created var> Age at date of pacemaker placement, days
PACERTY	B4b. Type of pacemaker
PACER_S	B4b1. Specify

B5. Arrhythmia requiring medication or intervention YES ..... 1 NO.....2 **(END)**

		YES	NO
a.	Intraatrial re-entrant tachycardia	1	2
b.	Supraventricular tachycardia	1	2
c.	Atrial flutter	1	2
d.	Atrial fibrillation	1	2
e.	Junctional ectopic tachycardia (> 170 bpm)	1	2
f.	Ventricular tachycardia	1	2
g.	Ventricular fibrillation	1	2
h.	Bradycardia requiring artificial pacemaker	1	2
i.	2 <sup>nd</sup> degree AV block	1	2
j.	3 <sup>rd</sup> degree AV block (complete heart block)	1	2
k.	Other	1	2 <b>(END)</b>
1. Other, specify:			

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ARRHYTH	B5. Arrhythmia requiring medication or intervention?
INTRATACH	B5a. Intraatrial re-entrant tachycardia
SUPRATACH	B5b. Supraventricular tachycardia
ATRIALFLUT	B5c. Atrial flutter
ATRIALFIB	B5d. Atrial fibrillation
JUNCTACH	B5e. Junctional ectopic tachycardia (> 170 bpm)
VENTTACH	B5f. Ventricular tachycardia
VENTFIB	B5g. Ventricular fibrillation
BRADYCAR	B5h. Bradycardia requiring artificial pacemaker
AVBLK2ND	B5i. 2nd degree AV block
AVBLK3RD	B5j. 3rd degree AV block (complete heart block)
ARRHYOTH	B5k. Other
ARRHYOTH_S	B5k1. Specify