

INSTRUCTIONS: All questions on this form refer to the time period from birth to entry into the operating room for the Norwood procedure.

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. Date of form completion
 _____ / _____ / _____ Y Y Y Y
 M M D D Y Y Y Y

Replaced by age (days) at R101 completion

R102_age	A3.<created var>Age at date of form completion, days
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A4. Name of person completing form _____
 PRINT FULL NAME _____ INITIALS _____

Removed to protect privacy

Section B: NEONATAL HISTORY

B1. APGAR score at 1 minute _____ (0-10)

APGAR1	B1. APGAR score at 1 minute
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B2. APGAR score at 5 minutes _____ (0-10)

APGAR5	B2. APGAR score at 5 minutes
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B3. Was lactate measured? YES..... 1 NO2 **(B4)** UNKNOWN -8 **(B4)**

a. Method ARTERIAL 1
 VENOUS.....2

b. Highest lactate _____ . _____ mmol/L

LACTATE	B3. Was lactate measured?
LACTMETH	B3a. Method
HIGHLACT	B3b. Highest lactate, mmol/L

B4. Ever intubated YES..... 1 NO2 **(B5)** UNKNOWN -8 **(B5)**

- a. Reason for first intubation
- APNEA..... 1
 - SHOCK..... 2
 - RESPIRATORY FAILURE 3
 - METABOLIC ACIDOSIS 4
 - TRANSPORT ONLY.....5
 - OTHER 99
 - UNKNOWN..... -8

INTUBAT	B4. Ever intubated
INTUB_R	B4a. Reason for first intubation

- B5. Inhaled gases: CO₂ YES..... 1 NO 2

GASCO2	B5. Inhales gases CO2
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- B6. Inhaled gases: N₂ YES..... 1 NO 2

GASN2	B6. Inhales gases N2
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Section C: PRE-NORWOOD MEDICAL and SURGICAL HISTORY

- C1. Number of interventional cardiac catheterization procedures prior to Norwood _____ (0-5) (If 0, skip to C2)
[DO NOT include diagnostic catheterizations]

Pre-Norwood 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.	_____					____ / ____ / ____

Pediatric Heart Network: Single Ventricle Reconstruction Trial

Form R102: Pre-Norwood Medical History
(Not All Dataset Variables are Shown)

		M M D D Y Y Y Y
		Name of intervention
c.	_____	____/____/____ M M D D Y Y Y Y
		Name of intervention
d.	_____	____/____/____ M M D D Y Y Y Y
		Name of intervention
e.	_____	____/____/____ M M D D Y Y Y Y
		Name of intervention

BNUMCATH	C1. Number of cardiac catheterization intervention prior to Norwood
precath	C1. <created var> Concatenation of all pre-Norwood cardiac catheterization codes
pre_cath_0	C1a. <created var>pre-Norwood cardiac catheterization
bcath_age_0	C1a. <created var> Age at pre-Norwood cardiac catheterization procedures, days
BCATHNAM_0	C1a. Name of cardiac catheterization
pre_cath_1	C1b. <created var>pre-Norwood cardiac catheterization
bcath_age_1	C1b. <created var>Age at pre-Norwood cardiac catheterization procedures, days
BCATHNAM_1	C1b. Name of cardiac catheterization
pre_cath_2	C1c. <created var>pre-Norwood cardiac catheterization
bcath_age_2	C1c. <created var> Age at pre-Norwood cardiac catheterization procedures, days
BCATHNAM_2	C1c. Name of cardiac catheterization

C2. Cardiac operative interventions performed in operating room or at bedside YES..... 1 NO..... 2 (C3)

	YES	NO	DATE
a. Atrial septectomy	1	2 (b)	___/___/_____
b. Left atrial decompression - balloon	1	2 (c)	___/___/_____
c. Left atrial decompression - stent	1	2 (d)	___/___/_____
d. Bilateral PA banding	1	2 (e)	___/___/_____

CARDINT	C2. Cardiac operative interventions performed
ATRSEP	C2a. Atrial septectomy
atrsep_age	C2a. <created var> Age at atrial septectomy performed in OR or at bedside, days
BALLOON	C2b. Left atrial decompression: Balloon
Balloon_age	C2b.<created var> Age at left atrial decompression - balloon performed in OR or at bedside, days
STENT	C2c. Left atrial decompression: Stent
stent_age	C2c.<created var> Age at left atrial decompression - stent performed in OR or at bedside, days
PABAND	C2d. Bilateral PA banding
paband_age	C2d.<created var> Age at bilateral PA banding in OR or at bedside, days

C3. Number of other surgical procedures prior to Norwood _____ (0-5) (If 0, skip to C4)

[DO NOT include cardiac interventions listed in C2 or catheterizations (C1) listed previously]

Other Surgical Procedures			
Code	Procedure Name	Code	Procedure Name
01	Bowel surgery		
05	Dialysis	17	Thoracentesis
07	Extracorporeal membrane oxygenation	19	Thoracostomy tube
		23	Ventriculostomy/VP shunt
		99	Other surgical procedure

Surgical Code (See codes above)

a. 1. _____ 2. If Other (99), specify: _____

3. Date / / Y Y Y Y
M M D D Y Y Y Y

b. 1. _____ 2. If Other (99), specify: _____

3. Date / / Y Y Y Y
M M D D Y Y Y Y

BNUMSURG	C3. Number of other surgical procedures
BSURGCOD_0	C3a1.Surgical procedure prior to Norwood
BSURG_age_0	C3a3. <created var> Age at other surgical procedures prior to Norwood, days
BSURG_S_0	C3a2.'Specify other' surgical procedure

Pediatric Heart Network: Single Ventricle Reconstruction Trial

Form R102: Pre-Norwood Medical History
(Not All Dataset Variables are Shown)

C4. Number of above procedures for which patient was _____ (0 – 5) (If 0 skip to C5)
placed on cardiopulmonary bypass

	a. Procedure code (see C3, Other Surgical Code list above; if procedure is described in C2, enter 99 for "other" and specify)	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: _____									

CPB	[Added version B]C4. Number of above procedures for which patient was placed...
CPB_EV_0	[Added version B]C4.1.a.. Procedure code
CPB_SPC_0	[Added version B]C4.1.a1.. Specify other procedure code
CPB_MN_0	[Added version B]C4.1.b.. Bypass time, minutes
DHCA_YN_0	[Added version B]C4.1.c.. On DHCA
DHCA_MN_0	[Added version B]C4.1.d.. DHCA time, minutes
RCP_YN_0	[Added version B]C4.1.e.. On RCP
RCP_MN_0	[Added version B]C4.1.f.. RCP time minutes
RCPFLOW_0	[Added version B]C4.1.g.. RCP flow, cc/kg/min
LOW_TEMP_0	[Added version B]C4.1.h.. Lowest temperature during bypass, celcius
HCT_PCT_0	[Added version B]C4.1.i.. HCT, percent

C5. Number of significant pre-Norwood complications ___ ___ (0-8) (If 0, **END**)

Complications Code
(See Code List M)
[Code required for data entry]

Specify
[Use spaces below to write complications]

a1. ___ - ___ ___ ___

a2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

b1. ___ - ___ ___ ___

b2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

c1. ___ - ___ ___ ___

c2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

d1. ___ - ___ ___ ___

d2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

e1. ___ - ___ ___ ___

e2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

f1. ___ - ___ ___ ___

f2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

g1. ___ - ___ ___ ___

g2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

h1. ___ - ___ ___ ___

h2. Date of onset

___ ___ / ___ ___ / ___ ___ ___ ___ M M / D D Y Y Y Y

bcompcode	C5. <created var> Concatenation of all pre-Norwood complication codes
BCOMP_COD_0	C5a1.Pre-NORWOOD complication
BCOMP_S_0	C5a. 'Specify other' complication
BCOMP_age_0	C5a2. <created var> Age at pre-Norwood complication, days
BCOMP_COD_1	C5b1.Pre-NORWOOD complication
BCOMP_S_1	C5b. 'Specify other' complication
BCOMP_age_1	C5b2.<created var> Age at pre-Norwood complication, days
BCOMP_COD_2	C5c1.Pre-NORWOOD complication
BCOMP_S_2	C5c. 'Specify other' complication
BCOMP_age_2	C5c2. <created var> Age at pre-Norwood complication, days

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BCOMP_COD_21	C5v1.Pre-NORWOOD complication
BCOMP_S_21	C5v. 'Specify other' complication
BCOMP_age_21	C5v2. <created var> Age at pre-Norwood complication, days
BCOMP_COD_22	C5w1.Pre-NORWOOD complication
BCOMP_S_22	C5w. 'Specify other' complication
BCOMP_age_22	C5w2. <created var> Age at pre-Norwood complication, days
BCOMP_COD_23	C5x1.Pre-NORWOOD complication
BCOMP_S_23	C5x. 'Specify other' complication
BCOMP_age_23	C5x2. <created var> Age at pre-Norwood complication, days