**APPENDIX 1**

**The Namibia children heart project; a 6-year retrospective review**

DATA COLLECTION FORM

# 1. DEMOGRAPHICS

Subject ID Number: (Sequential number plus patient initials): \_\_\_\_\_\_\_\_\_\_\_\_

Geographical Region:

1. Erongo
2. Hardap
3. Kavango
4. Khomas
5. Ohangwena
6. Omaheke
7. Oshana
8. Oshikoto
9. Otjozondjupa
10. Zambezi

Date of birth (DD /MM /YYYY): \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Date of initial presentation at Windhoek facility: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Age at presentation (auto-calculated): \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (MONTHS)

Cape Town facility Admission date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Cape Town facility Discharge date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Age at admission to Cape Town facility (auto-calculated): \_\_\_\_\_\_\_\_\_\_\_\_\_ (MONTHS)

Sex:

1. M
2. F
3. Other/Missing

2. DIAGNOSIS(According to the ICD.10 coding system Appendix 2.)

Primary Cardiac Dx Code: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Type of Heart Disease

1. Acquired
   1. Takayau’s Arteritis
   2. Rheumatic Heart Disease
2. Congenital
   1. Coarctation of Aorta
   2. Interrupted Aortic Arch
   3. Sub-aortic Stenosis
   4. Valvar Aortic stenosis
   5. Tricuspid Atresia
   6. Double Inlet Left Ventricle
   7. Double Outlet Right Ventricle
   8. Mitral Stenosis
   9. Double Orifice Mitral Valve
   10. Mitral Valve Prolapse
   11. Other. Pls describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Additional lesions:

1. None
2. Total Anomalous Pulmonary Venous Drainage
3. Partial Anomalous Pulmonary Venous Drainage
4. Atrio-ventricular Disconcordance
5. Ventriculo-arterial Disconcordance
6. Isomeric atrial appendages
7. Other: Please describe\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Other relevant diagnoses:

Diagnosis 2: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Diagnosis 3: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Diagnosis 4: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Diagnosis 5: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Diagnosis 6: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (xxx.xx)

Other/Missing: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (999)

Co-morbidities /Associations/Syndromes

1. HIV
2. Diaphragmatic hernia
3. Down syndrome
4. Noonan’s syndrome
5. Shone Complex
6. Pulmonary TB
7. Congenital Rubella
8. George’s Syndrome
9. Isolated midline defects
10. Skeletal abnormalities (e.g. kyphosis, scoliosis, radial)
11. VACTERL association
12. Congenital renal abnormalities
13. Other: Please describe\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Pregnant at time of intervention?

1. Yes

If yes, gestational age: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (weeks)

1. No
2. Unknown/Missing

RACHS Category score:

☐1. ☐2. ☐3. ☐4. ☐5. ☐6.

Was patient returned to WCH because of contraindications for surgery?

* 1. Yes
  2. No
  3. Other

If yes, Please describe the nature of the contraindication

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Outcome:

1. Patient was readmitted for intervention at a later date (within the review period)
2. Patient was deemed as an inappropriate candidate for surgery with no plans for further intervention

3. CATHETERISATION

1. Yes
2. No. If no, please proceed to Section.4 below.

If yes,

Date of catheterization: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (MM/ DD /YYYY)

Age at catheterization: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (MONTHS)

Primary Indication for catheterization (tick one of the below):

1. Diagnostic

2. Haemodynamic

3. Interventional

**If Diagnostic**, please complete this section

1. Outcome
   1. Not amenable to surgery or other intervention
      1. Complex and inoperable anatomy
      2. Irreversible PHT
   2. Found to be suitable candidate for surgery
   3. Found to be suitable candidate for interventional catheterization
   4. Other. Please describe.---------------------
2. Catheterization Complications?
3. Yes
4. No
5. If yes, (can indicate more than one)
6. Arrhythmia
7. Bleeding
8. Cardiac arrest
9. Pulmonary hypertensive crisis
10. Death
11. Other/Missing

**If Haemodynamic,** please complete this section

Outcome

1. Irreversible pulmonary obstructive vascular disease
2. Reversible pulmonary obstructive vascular disease
3. Other. Please describe.---------------------

Baseline Pulmonary vascular resistance index: \_\_\_\_\_\_\_\_\_\_\_ (xx.xx)

Post O2 administration pulmonary vascular resistance index: \_\_\_\_\_\_ (xx.xx)

Catheterization Complications?

1. Yes
2. No
3. Unknown/Missing

If yes, (can indicate more than one)

1. Arrhythmia
2. Bleeding
3. Cardiac arrest
4. Death
5. Pulmonary hypertensive crisis
6. Other/Missing

**If Interventional**, please complete this section

Outcome

1. ASD device closure

Successful?

1. Yes 2. No

1. PDA device closure

Successful?

1. Yes 2. No

1. Aortic stenting

Successful?

1. Yes 2. No

Site of stenting: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)

1. RVOT/branch pulmonary arteries stenting

Successful?

1. Yes 2. No

1. Percutaneous mitral valvuloplasty

Successful?

1. Yes 2. No

3. Initial mean gradient: \_\_\_\_\_ mmHg

4. Post valvuloplasty mean gradient: \_\_\_\_\_mmHg

1. Percutaneous mitral valvuloplasty

Successful?

1. Yes 2. No

Initial mean gradient: \_\_\_\_\_mmHg

Post valvuloplasty mean gradient: \_\_\_\_\_mmHg

1. Radiofrequency ablation

Successful?

1. Yes 2. No

1. Other. Pls describe: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Successful?

1. Yes 2. No

Catheterization Complications?

1. Yes 2. No

If yes, (can indicate more than one)

1. Arrhythmia

2. Bleeding

3. Cardiac arrest

4. Death

5. Pulmonary hypertensive crisis

6. Other/Missing

4. SURGERY

1. Yes
2. No

If no, why not?

* + 1. Deemed inoperable
    2. Advanced pulmonary obstructive vascular disease
    3. Complex anatomy
    4. Unknown/Missing

If no, proceed to next section.

If yes,

Date of Surgery: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Type:

1. Elective

2. Emergency

3. Re-operation

If re-operation, date of previous surgery: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Palliative surgery?

1. Yes

2. No

If yes,

1. Central shunt
2. Glenn shunt
3. PA banding
4. LMBTS
5. RMBTS
6. TCPC
7. Other. Please describe: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)

Definitive surgery?

1. Yes

2. No

If yes,

1. Aortic valve replacement
2. Arterial switch procedure
3. ASD repair
4. AVSD repair
5. Coarctation repair
6. Interrupted aortic arch repair
7. Mitral valve replacement
8. PDA ligation
9. Ross- Konno procedure
10. TAPVD Repair
11. Tetralogy of Fallot repair
12. VSD repair
13. Other. Please describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)

Bypass time: \_\_\_\_\_\_\_\_\_ (Minutes)

Cross-clamp time: \_\_\_\_\_\_\_\_\_\_ (Minutes)

Other incidental surgeries?

1. None
2. Cleft palate repair
3. Diaphragmatic hernia repair
4. Diaphragm plication
5. Percutaneous gastrostomy
6. Other. Please describe. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)
7. Unknown/Missing

5. COMPLICATIONS

Primary post-operative complications

1. None
2. Arrhythmia
3. Bleeding
4. Cardiac failure
5. Chylothorax
6. Diaphragmatic Paralysis
7. Infection
8. Pleural effusion
9. Pericardial effusion
10. Pulmonary hypertensive crisis
11. Seizures
12. Other: Please describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_(text)

Residual defects

1. Yes 2. No

If yes

* + 1. Requiring further intervention Describe\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)
    2. No further intervention required

Describe \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)

# 6. DEATH

1. Yes
2. No

If yes,

* + 1. Intraoperative Death
    2. Early postoperative mortality
    3. \*Late postoperative mortality
    4. Unknown/Missing

Date of death: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Cause of Death:

1. Respiratory failure
2. Post-operative low cardiac output syndrome
3. Right heart failure
4. Myocardial infarction
5. Refractory ventricular tachyarrhythmia
6. Traumatic pericardiocentesis
7. Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)
8. Missing/Unknown

# 7. INPATIENT DAYS

Number of days in PICU/ICU post-surgery: \_\_\_\_\_\_\_\_\_\_\_\_\_ (0 to XX)

Number of days in hospital: \_\_\_\_\_\_\_\_\_\_\_\_\_ (0 to XXX)

Date of discharge back to Windhoek: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

# 8. FOLLOW-UP DETAILS

\*Has patient died since returning to Namibia (late mortality)?

1. Yes

If yes,

Date of death \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Cause of death if known \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)

1. No

If no,

Most recent follow up appointment date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ (DD/MM/YYYY)

Number of kept follow up appointments since intervention: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Number of expected follow up appointments since intervention: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Unknown, lost to follow up

Number of attempts to trace patient:

1. <5
2. >5

Details: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ (text)