**Supplementary Material**

**Survey Administered to Participants:**

**Please select your role**:

Physician

Nurse Practitioner

Physician Assistant

Registered Nurse

Social Worker

Child Life Specialist

Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Please select your years of clinical experience**:

1 – 4

5 – 9

10 – 14

15 – 19

20 or more

1. Have you ever been involved in the care of a patient with hypoplastic left heart syndrome?

Yes

No

If yes, approximately how many hypoplastic left heart syndrome patients have you cared for?

1 – 4

5 – 9

10 – 14

15 – 19

20 or more

1. Please rate your level of agreement with the following statement:

All patients diagnosed prenatally with hypoplastic left heart syndrome should have a pediatric palliative care consult.

Strongly agree

Agree

Disagree

Strongly disagree

1. Based on your experience, when do you believe the initial pediatric palliative care consult should occur for hypoplastic left heart syndrome patients and families?

Prenatal period

Prior to initial surgical intervention

After initial surgical intervention

When complications in treatment regimen occur

When redirection of care toward comfort is being considered

Never

Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Please rate your level of agreement with the following statements:

Implementing prenatal pediatric palliative care consults as standard of care for hypoplastic left heart syndrome patients improves…

Advance care planning for patients and families – Strongly agree Agree Disagree Strongly disagree

Quality of life for patients and families – Strongly agree Agree Disagree Strongly disagree

Transition from hospital to home care – Strongly agree Agree Disagree Strongly disagree

1. Please evaluate the impact pediatric palliative care has on the management of hypoplastic left heart syndrome patients in terms of the following:

**1**: Very helpful

**2**: Helpful

**3**: No effect

**4**: Unhelpful

**5**: Very unhelpful

Pain and symptom management of patient – 1 2 3 4 5

Moral distress of staff – 1 2 3 4 5

Psychosocial support of parents – 1 2 3 4 5

Psychosocial support of siblings – 1 2 3 4 5

Bereavement support of family – 1 2 3 4 5

1. Until recently,prenatal pediatric palliative care consults were not typically provided for hypoplastic left heart syndrome patients and families at Doernbecher Children’s Hospital. At present, all patients and families with hypoplastic left heart syndrome receive pediatric palliative care consults in the prenatal period.
   1. What do you believe are the positive aspects of this new referral protocol?
   2. What are your concerns about this new referral protocol?
2. Based on your experience, has prenatal integration of pediatric palliative care into the treatment of hypoplastic left heart syndrome patients altered their treatment course?

Yes

No

If yes, please explain the modifications in the treatment course that you have observed or implemented.

1. In addition to hypoplastic left heart syndrome, are there other conditions diagnosed before birth that you believe should routinely have a prenatal pediatric palliative care consult? Please select all that apply. If applicable, add other suggestions below.

Truncus arteriosus

Transposition of great vessels

Tetralogy of Fallot with severe pulmonary stenosis

Heterotaxy syndrome

Any congenital heart disease diagnosis that requires surgical intervention in the first year of life

Other suggestions:

1. Please rate your level of agreement with the following statement:

Including pediatric palliative care consults as standard of care for hypoplastic left heart syndrome patients and families negatively impacts the relationship non-palliative care clinicians have with the patient and family.

Strongly agree

Agree

Disagree

Strongly disagree

1. Please rate your level of agreement with the following statement:

Implementing required pediatric palliative care consults for fetuses diagnosed with hypoplastic left heart syndrome decreases the barriers to making a referral to pediatric palliative care services.

Strongly agree

Agree

Disagree

Strongly disagree

1. Please rate your level of agreement with the following statement:

Palliative care is at odds with simultaneous delivery of therapies directed at cure or long-term survival.

Strongly agree

Agree

Disagree

Strongly disagree

1. Based on your understanding, what can pediatric palliative care provide? Check all that apply.

Counseling and education

Pain and symptom management

Spiritual, religious and cultural services

Family portraits for children and families

Assistance with securing community home or hospice care

Family bereavement services

Annual memorial

Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. Please add any additional comments you have about the implementation of pediatric palliative care consults for patients and families with hypoplastic left heart syndrome during the prenatal period.