

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Introduction

Thank you for taking part in this national survey.

We are seeking your views to better understand and improve services for children with complex cardiac conditions, their parents and professionals caring for them.

We estimate that the survey will take approximately 10 minutes to complete. Your responses cannot be saved so for your views to be shared, you must finish the survey after opening it. The deadline for survey completion is 30 June 2018.

We greatly appreciate your time and input

If you have any questions about the survey or would like more information, please contact Sid Vemuri (s.vemuri@ucl.ac.uk).

By continuing with this survey you acknowledge that:

- **Submission of the survey indicates your consent to participate.**
- **All responses are anonymous and neither you nor your institution will be identifiable.**
- **Participation is entirely voluntary and you may cease answering questions at any time you wish.**
- **Once you have submitted the survey your data cannot be withdrawn.**

*** 1. Do you agree to continue with this survey?**

☐ Yes

☐ No

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Screening for inclusion

* 2. Does your practice include clinical care for **children with complex cardiac conditions**?

☐ Yes

☐ No

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Demographics

* 3. Gender

- ☐ Male
- ☐ Female
- ☐ Prefer not to say

* 4. Please select your profession/occupation

- ☐ Doctor
- ☐ Nurse
- ☐ Other (please specify)

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Demographics

5. Please select your role

- ☐ Consultant
- ☐ Specialty or Associate Grade doctor
- ☐ Trainee

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

6. Please select your current band

- ☐ Band 5
- ☐ Band 6
- ☐ Band 7 or above

* 7. Please select your primary professional affiliation

- ☐ Hospital-based palliative care team
- ☐ Children's hospice
- ☐ Community-based palliative care team
- ☐ Other (please specify)

* 8. How long have you worked in your current role?

- ☐ Less than 1 year
- ☐ 1-3 years
- ☐ 4-6 years
- ☐ 7-9 years
- ☐ 10 years or more

* 9. Which of the following is your **primary field**?

- ☐ General practice
- ☐ Community children's nursing
- ☐ Children's hospice care
- ☐ Children's community palliative care
- ☐ General paediatrics
- ☐ Specialist paediatric palliative care

* 10. Do you participate in any prenatal consultations?

- ☐ Yes
- ☐ No

* 11. Does your main referring institution have a **separate** cardiac intensive care unit?

- ☐ Yes
- ☐ No

* 12. On average, what percentage of children who you have provided end of life care to in a given year have had a complex cardiac condition?

- ☐ <1%
- ☐ 1-5%
- ☐ 5-25%
- ☐ 25-50%
- ☐ >50%
- ☐ Unsure

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Clinical practice and experience

* 13. When a child may have a poor outcome, do you think there are **barriers** to discussing goals of care?

☐ Yes

☐ No

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Clinical practice and experience

14. Please describe the barriers

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Clinical practice and experience

* 15. To what extent do you agree or disagree with the following statements

	Strongly disagree	Disagree	Agree	Strongly agree
Palliative care is primarily about providing care at the end of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no role for palliative care involvement unless the child is expected to die within weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care referral would be acceptable to the parents of most of the children with complex cardiac conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents' hope will be undermined if the option for planning care and treatment in anticipation of a child's potential poor outcome (including death) is provided too early	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When a diagnosis with a likely poor outcome is made, parents are routinely offered referral to the palliative care team before management for the child has been agreed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When there are conflicting disease-specific professional views on the approach to management of a child, a referral to the palliative care team can be helpful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young people are capable of playing a role in decision-making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A palliative care team can assist in symptom management for a child with complex cardiac conditions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 16. In general, how **confident** do you feel with the following clinical activities

	Very confident	Confident	Not confident	Not at all confident
Discussing the goals of care with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing resuscitation status with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing concerns about death and dying with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for a child who is deteriorating over hours-to-days with no realistic chance for survival	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prognosticating life expectancy for a child with a complex cardiac condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing the option of dying at home, in the hospice or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Offering advice in the care of a child with a complex cardiac condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care to a child with a complex cardiac condition during the 'end-of-life care period' (defined as the time after which you realise that the child has no realistic chance for survival)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 17. Please select if you are **confident** discussing with a **young person** (please check all that apply)

	Goals of care	Resuscitation status	Concerns about death and dying
Aged 12 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aged 16 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Palliative care involvement in the care of children with complex cardiac conditions

- * 18. To what extent do you agree or disagree that a palliative care team could provide valuable support to clinicians caring for children with complex cardiac conditions

Strongly disagree	Disagree	Agree	Strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- * 19. In the last year, how often have you received referrals from clinicians caring for children with complex cardiac conditions?

Never	Rarely	Occasionally	Regularly
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- * 20. Why have children with complex cardiac conditions been referred to you? (Please select all that apply)

- ☐ To support parents in decision making
- ☐ To assist in discussions with parents around expected outcomes and expectations
- ☐ To allow parents to plan care in the event of a potential poor outcome for the child
- ☐ To provide symptom management to the child or young person
- ☐ To discuss DNAR status with parents
- ☐ To discuss with the parents the option of the child or young person dying at home or in a hospice
- ☐ To discuss the issues of illness and dying with the parents and/or child or young person
- ☐ To assist in finding a resolution of differences between the team and parents wishes for care
- ☐ Other (please specify)

- * 21. In general, do you feel that children who were **referred to palliative care** were referred

At the appropriate time	Too early	Too late
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Palliative care involvement

22. When would be the more appropriate time to refer to palliative care?

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

Scenarios

* 23. Do you think the children in the following clinical scenarios should be referred to palliative care?

	Definitely	Probably	Occasionally	Definitely not
Child where there are no further surgical management options technically possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unborn child with an antenatal diagnosis of a single ventricle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a ventricular assist device in-situ	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition and a major genetic disorder (excluding trisomy 21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with symptomatic heart failure from myocardial dysfunction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition who requires ongoing ICU/HDU admission 30-days after their initial procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child requiring ECMO	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being planned for an implantable cardiac defibrillator	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being planned for a ventricular assist device	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Newborn child with a single ventricle proceeding with surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child listed and awaiting heart transplantation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where there is lack of professional consensus within the treating team regarding the plan of care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 24. In the following clinical scenarios, please select and rank the most useful sources of additional support for the treating clinician

Colleague in their team

Clinical ethics panel

Palliative Care team

Scenario: Child with a single ventricle, post first-stage palliative surgery, who has recurrent cardiac arrests

Issue: The family want full resuscitation but the treating clinician wants to limit ongoing resuscitation interventions

Scenario: Extremely premature child, now two months corrected age, with chronic lung disease, who has required multiple dilatations for pulmonary vein stenosis affecting all pulmonary veins

Issue: The family want to pursue surgical repair but the treating clinician feels this should not be offered

Scenario: Child who has remained in the intensive care for six months with CPAP dependence, following palliative cardiac surgery

Issue: The family want a tracheostomy inserted but the treating clinician does not feel it should be offered

Scenario: Child with trisomy 21, failure to thrive and corrected congenital heart disease

Issue: The family want to remove the nasogastric tube and continue with oral feeding only, but the treating clinician thinks the child would benefit from ongoing nasogastric feeds and/or gastrostomy insertion

Paediatric palliative care providers' perspectives and practices in the care of children with complex cardiac conditions

25. Any other comments regarding palliative care involvement in children with complex cardiac conditions

Thank you for your participation.

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Introduction

Thank you for taking part in this national survey.

We are seeking your views to better understand and improve services for children with complex cardiac conditions, their parents and professionals caring for them.

We estimate that the survey will take approximately 10 minutes to complete. Your responses cannot be saved so for your views to be shared, you must finish the survey after opening it. The deadline for survey completion is 31 August 2018.

We greatly appreciate your time and input.

If you have any questions about the survey or would like more information, please contact Sid Vemuri (s.vemuri@ucl.ac.uk).

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- **All responses are anonymous and neither you nor your institution will be identifiable.**
- **Participation is entirely voluntary and you may cease answering questions at any time you wish.**
- **However, once you have submitted the survey your data cannot be withdrawn.**

*** 1. Do you agree to continue with this survey?**

☐ Yes

☐ No

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Screening for inclusion

* 2. Does your practice include clinical care for **children with complex cardiac conditions**?

☐ Yes

☐ No

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Demographics

* 3. Gender

- ☐ Male
- ☐ Female
- ☐ Prefer not to say

* 4. Please select your profession/occupation

- ☐ Doctor
- ☐ Nurse
- ☐ Other (please specify)

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Demographics

5. Please select your current role

- ☐ Consultant
- ☐ Specialty or Associate Grade doctor
- ☐ Trainee

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

6. Please select your current band

- ☐ Band 5
- ☐ Band 6
- ☐ Band 7 or above

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Demographics

* 7. Specialty

- ☐ Cardiology
- ☐ Intensive care
- ☐ Cardiac surgery
- ☐ General paediatrics

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Demographics

* 8. Which of the following is your **primary field**?

- | | |
|---|--|
| <input type="radio"/> General cardiology | <input type="radio"/> Heart failure/transplant |
| <input type="radio"/> Fetal cardiology | <input type="radio"/> Electrophysiology |
| <input type="radio"/> Single ventricle service | <input type="radio"/> Cardiac imaging |
| <input type="radio"/> Interventional cardiology | |

* 9. How long have you worked in your current role?

- | | |
|--|--|
| <input type="radio"/> Less than 1 year | <input type="radio"/> 7-9 years |
| <input type="radio"/> 1-3 years | <input type="radio"/> 10 years or more |
| <input type="radio"/> 4-6 years | |

* 10. Do you conduct any **prenatal consultations**?

- ☐ Yes
- ☐ No

* 11. Does your institution have a **separate** cardiac intensive care unit?

- ☐ Yes
- ☐ No

* 12. Does your institution have access to a palliative care team?

- ☐ Yes
- ☐ No
- ☐ Unsure

* 13. Have you had any professional experience with a (please select all that apply)

- ☐ Hospital-based palliative care team
- ☐ Children's hospice
- ☐ Community-based palliative care team

* 14. On average, what percentage of children under your care have died in a given year?

☐ <1%

☐ 25-50%

☐ 1-5%

☐ >50%

☐ 5-25%

☐ Unsure

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Clinical practice and experience

* 15. When faced with a child who may have a poor outcome, do you think there are **barriers** to discussing goals of care?

☐ Yes

☐ No

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Palliative care involvement

16. Please describe the barriers

* 17. To what extent do you agree or disagree with the following statements

	Strongly disagree	Disagree	Agree	Strongly agree
Palliative care is primarily about providing care at the end of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no role for palliative care involvement unless the child is expected to die within weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Palliative care referral would be acceptable to the parents of most of the children I look after	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parents' hope will be undermined if the option for planning care and treatment in anticipation of a child's potential poor outcome (including death) is provided too early	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When a diagnosis with a likely poor outcome is made, parents are routinely offered referral to the palliative care team before management for the child has been agreed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When there are conflicting professional views on the approach to management, a referral to the palliative care team can be helpful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Young people are capable of playing a role in decision-making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A palliative care team can assist in symptom management in the children I look after	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 18. In general, how **confident** do you feel with the following clinical activities

	Very confident	Confident	Not confident	Not at all confident
Discussing goals of care with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing resuscitation status with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing concerns about death and dying with parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Caring for a child who is deteriorating over hours-to-days with no realistic chance for survival	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prognosticating life expectancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing the option of dying at home, in the hospice or hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referral to a palliative care team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Providing care to a child with heart disease during the 'end-of-life care period' (defined as the time after which you realise that the child has no realistic chance for survival)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. Please select if you are **confident** discussing with a **young person** (please check all that apply)

	Goals of care	Resuscitation status	Concerns about death and dying
Aged 12 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Aged 16 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Palliative care involvement

* 20. To what extent do you agree or disagree that a palliative care team can provide valuable support to your team

Strongly disagree	Disagree	Agree	Strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 21. In the last year, how often have you made referrals or encouraged others to make a referral to the palliative care team?

- ☐ Never
- ☐ Rarely
- ☐ Occasionally
- ☐ Regularly

* 22. When would you consider making a referral to a palliative care service? (Please select all that apply)

- | | |
|---|--|
| <input type="checkbox"/> To support parents in decision making | <input type="checkbox"/> To discuss DNAR status with parents |
| <input type="checkbox"/> To assist in discussions with parents around expected outcomes and expectations | <input type="checkbox"/> To discuss with the parents the option of the child or young person dying at home or in a hospice |
| <input type="checkbox"/> To allow parents to plan care in the event of a potential poor outcome for the child | <input type="checkbox"/> To discuss the issues of illness and dying with the parents and/or child or young person |
| <input type="checkbox"/> To provide symptom management to the child or young person | <input type="checkbox"/> To assist in finding a resolution of differences between the team and parents wishes for care |
| <input type="checkbox"/> Other (please specify) | |
| <input type="text"/> | |

* 23. In general, do you feel that the children who were referred to palliative care were referred

At the appropriate time	Too early	Too late	Not applicable, as no children I look after are referred to palliative care
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Palliative care involvement

24. When would be the more appropriate time to refer to palliative care?

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

Scenarios

* 25. Do you think the children in the following clinical scenarios should be referred to palliative care

	Definitely	Probably	Occasionally	Definitely not
Child where there are no further surgical management options technically possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unborn child with an antenatal diagnosis of a single-ventricle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a ventricular assist device in-situ	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition and a major genetic disorder (excluding trisomy 21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with symptomatic heart failure from myocardial dysfunction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition who requires ongoing ICU/HDU admission 30-days after their initial procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child requiring ECMO	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being planned for an implantable cardiac defibrillator	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being planned for a ventricular assist device	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Newborn child with a single-ventricle proceeding with surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child listed and awaiting heart transplantation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where there is lack of professional consensus within the team regarding the plan for care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 26. In the following clinical scenarios, please select and rank who you would go to for assistance

Colleague in my unit

Clinical ethics panel

Palliative care team

Scenario: Child with a single ventricle, post first-stage palliative surgery, who has recurrent cardiac arrests

Issue: The family want full resuscitation but you want to limit ongoing resuscitation interventions

Scenario: Extremely premature child, now two months corrected age, with chronic lung disease, who has required multiple dilatations for pulmonary vein stenosis affecting all pulmonary veins

Issue: The family want to pursue surgical repair but you feel this should not be offered

Scenario: Child who has remained in the intensive care unit for six months with CPAP dependence following palliative cardiac surgery

Issue: The family want a tracheostomy inserted but you do not feel it should be offered

Scenario: Child with trisomy 21, failure to thrive and repaired congenital heart disease

Issue: The family want to remove the nasogastric tube and continue with oral feeding only, but you think the child would benefit from ongoing nasogastric feeds or gastrostomy insertion

Paediatric cardiology care providers' perspectives and practices towards palliative care involvement in the care of children with complex cardiac conditions

27. Any other comments regarding palliative care involvement in children with complex cardiac conditions

Thank you for your participation.