



OPEN ACCESS

# Palliative care for children with complex cardiac conditions: survey results

Sidharth Vemuri <sup>1,2</sup>, Ashleigh E Butler <sup>2,3</sup>, Katherine Brown <sup>4,5</sup>,  
Jo Wray <sup>4,5,6</sup>, Myra Bluebond-Langner <sup>2,7</sup>

► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/archdischild-2020-320866>).

<sup>1</sup>Victorian Paediatric Palliative Care Program, The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia

<sup>2</sup>Louis Dundas Centre for Children's Palliative Care, University College London Great Ormond Street Institute for Child Health, London, UK

<sup>3</sup>Austin Health Clinical School, School of Nursing and Midwifery, La Trobe University, Melbourne, Victoria, Australia

<sup>4</sup>Institute of Cardiovascular Science, University College London, London, UK

<sup>5</sup>Heart Lung Directorate, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

<sup>6</sup>Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

<sup>7</sup>Rutgers University, Camden, New Jersey, USA

## Correspondence to

Professor Myra Bluebond-Langner, Louis Dundas Center for Children's Palliative Care, University College London Great Ormond Street Institute for Child Health, London WC1N 1EH, UK; [bluebond@ucl.ac.uk](mailto:bluebond@ucl.ac.uk)

Received 5 October 2020

Accepted 3 July 2021



© Author(s) (or their employer(s)) 2021. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

**To cite:** Vemuri S, Butler AE, Brown K, et al. *Arch Dis Child* Epub ahead of print: [please include Day Month Year]. doi:10.1136/archdischild-2020-320866

## ABSTRACT

**Objective** To explore perspectives of paediatric cardiac and palliative care professionals on providing palliative care to children with complex cardiac conditions.

**Design** A national survey including closed-ended and open-ended questions as well as clinical scenarios designed to capture referral practices, attitudes towards palliative care, confidence delivering key components of palliative care and perspectives on for whom to provide palliative care. Responses to closed-ended questions and scenarios were analysed using descriptive statistics. Open-ended responses were analysed thematically.

**Participants** Paediatric cardiac and palliative care professionals caring for children with complex cardiac conditions in the UK.

**Results** 177 professionals (91 cardiac care and 86 palliative care) responded. Aspects of advance care planning were the most common reasons for referral to palliative care. Palliative care professionals reported greater confidence than cardiac colleagues with such discussions. Clinicians agreed that children with no further surgical management options, comorbid genetic disorders, antenatal diagnosis of a single ventricle, ventricular device in situ, symptomatic heart failure and those awaiting heart transplantation would benefit from palliative care involvement.

**Conclusions** Components of palliative care, such as advance care planning, can be provided by cardiac care professionals alongside the disease-directed care of children with complex cardiac conditions. Further research and training are needed to address confidence levels in cardiac care professionals in delivering components of palliative care as well as clarification of professional roles and parent preferences in delivery of family-centred care for children with complex cardiac conditions.

## INTRODUCTION

Approximately 15%–20% of children with major heart conditions have high-risk complex cardiac conditions.<sup>1</sup> While survival rates for these children have improved,<sup>2,3</sup> not all have a successful outcome.<sup>4–7</sup> Death is more likely to occur in the first year of life, commonly in high-acuity settings following withdrawal of intensive therapies.<sup>5,8</sup> Parents report significant suffering of their child at their end of life and may only realise their child was dying within their last 24 hours.<sup>4</sup> Those who survive their first year do so with complex morbidity<sup>9</sup> and ongoing possibility of early death.<sup>10,11</sup>

Given these risks, there is an increasing call to provide palliative care alongside disease-directed

## What is already known on this topic?

- Despite improved operative survival rates, children with complex cardiac conditions have a high burden of morbidity and risk of death in childhood.
- Palliative care delivered in parallel to disease-directed care is recognised as beneficial.
- The specific roles for palliative and cardiac care professionals delivering key components of palliative care to children with complex cardiac conditions are unclear.

## What this paper adds?

- Children antenatally diagnosed with single ventricle disease, no surgical options, ventricular device in situ, comorbid disorders, heart failure or awaiting transplantation should have palliative care involvement.
- Identification of cardiac care professionals' self-reported lack of confidence in conducting advance care planning discussions with parents.
- Support for development and study of parental views of packages of care integrating principles of palliative care into care for children with complex cardiac conditions.

management.<sup>11–13</sup> By planning disease-directed and palliative care in parallel, clinicians can better address parental concerns, improve parental well-being and broaden the focus of parent–clinician discussions.<sup>14–20</sup> Specifically, palliative care professionals (PCPs) can support complex decision-making, particularly regarding advance care planning, and improve the quality of life for children with complex cardiac conditions and their families throughout the illness,<sup>10,11,13</sup> not just at the end of life.

In the UK, children with complex cardiac conditions receive care in 1 of 16 paediatric cardiac centres, 11 with cardiac surgical facilities,<sup>21</sup> including 2 with cardiothoracic transplant programmes. PCPs, predominantly nurses, largely provide direct care in community and hospice settings. Most medical PCPs are paediatricians or general practitioners with special interests in palliative care.<sup>22</sup>

Despite increasing interest in incorporating palliative care into the care of children with complex cardiac conditions, referrals remain low<sup>4,23</sup> and the

specific role of PCPs in this context remains largely unexplored. This study addresses this gap through an examination of current referral practices, attitudes, confidence levels and perspectives of cardiac care professionals (CCPs) and PCPs who provide palliative care to children with complex cardiac conditions.

## METHODS

### Study design

This national cross-sectional e-survey study was registered at the Great Ormond Street Hospital National Health Service Foundation Trust and was exempt from research ethics committee review. Deidentified data with no institutional-based linkage were collected.

### Inclusion criteria

CCPs and PCPs, regardless of discipline, who care for children with complex cardiac conditions in the UK.

### Recruitment

An invitation and secure email link were distributed to members of the: Paediatric Intensive Care Society Study Group, British Congenital Cardiac Association, Congenital Cardiac Nurses Association, Association for Paediatric Palliative Medicine and Royal College of Nursing's Children's Palliative Care Special Interest Group. Snowball sampling was encouraged. The survey remained open from 20 June 2018 to 31 August 2018.

### The survey

The survey aimed to identify current practices, attitudes, confidence and perspectives of participants on providing palliative care to children with complex cardiac conditions. The survey (online supplemental file 1) was divided into six parts: (1) non-identifiable participant demographics, (2) palliative care referral practices, (3) attitudes towards palliative care and its key components, (4) confidence delivering key components of palliative care, (5) palliative care involvement in clinical scenarios, (6) open-ended questions exploring the appropriate time for referral, barriers to discussing goals of care when a child may have a poor outcome and additional comments regarding palliative care involvement.

Questions and topics included items used in previous surveys,<sup>8 24 25</sup> new items, as well as clinical scenarios developed using existing literature<sup>10</sup> in consultation with PCPs and CCPs. The surveys were hosted on SurveyMonkey.<sup>26</sup>

### Data analysis

#### Quantitative analysis

Descriptive analysis was performed using SPSS.<sup>27</sup> Data related to current referral practices were discrete response choices that were summarised according to percentage of either PCP or CCP who selected each response option. Data from questions related to attitudes towards palliative care and its key components, confidence delivering the key components and palliative care involvement in clinical scenarios were obtained from a 4-point Likert scale. These data, predominantly presented graphically, were summarised according to the proportion of responses made by PCPs or CCPs. A two-sided Mann-Whitney U test with continuity and tie corrections, with p value set at  $\leq 0.05$ , was used to test differences between responses of each group—PCPs and CCPs. We then dichotomised these data to analyse level of agreement/disagreement or confidence within each group. When considering the views of participants, we used an a priori level of 75% to indicate overall agreement/disagreement or confidence in each statement or activity. Statistical details

**Table 1** Participant demographics

Characteristic	PCPs (n=86)	CCPs (n=91)	P value
Female	74 (87.1%)	72 (79.1%)	0.368
Clinical role			0.010
Nurse	37 (43.5%)	59 (64.8%)	
Doctor	46 (54.1%)	30 (33%)	
Other	2 (2.4%)	2 (2.2%)	
Specialty			
Hospital-based team	19 (22%)	—	
Community-based team	8 (9.3%)	—	
Children's hospice	25 (29.1%)	—	
>1 listed affiliation	11 (12.8%)	—	
Cardiology	—	37 (40.7%)	
Intensive care	—	46 (50.5%)	
Cardiac surgery	—	2 (2.2%)	
Other	14 (16.3%)	6 (6.6%)	
No response	9 (10.5%)	0	
Seniority*	63 (76.8%)	58 (65.9%)	0.130
Years in current position			0.124
<1	9 (11.5%)	7 (7.9%)	
1–3	19 (24.4%)	17 (19.1%)	
4–6	14 (17.9%)	20 (22.5%)	
7–9	15 (19.2%)	8 (9.0%)	
>10	21 (26.9%)	37 (41.6%)	
Conducts prenatal consultations	37 (47.4%)	11 (12.4%)	<0.001
Institution has separate cardiac ICU	27 (34.6%)	61 (68.5%)	<0.001

\*Band 7 (senior clinical nurses, nurse managers) or higher or consultant position. CCPs, cardiac care professionals; ICU, intensive care unit; PCPs, palliative care professionals.

of results not presented graphically are in the text. Supporting numerical data are available in online supplemental file 2.

### Qualitative analysis

Responses to open-ended questions were analysed thematically with reference to closed-ended questions and clinical scenarios thereby capturing both a priori themes from the survey and literature as well as newly emerging themes. Qualitative data analysis was managed in NVivo.<sup>28</sup>

## RESULTS

### Participants

Two-hundred and one professionals commenced the survey. Thirteen did not go beyond the initial screening questions, eight did not answer any survey questions and three did not identify as PCPs or CCPs. Of the 177 included professionals, 86 identified as PCPs and 91 as CCPs. Demographics are described in [table 1](#).

### Current palliative care referral practices

The most commonly reported reasons for referral of children to PCPs were for: assistance with preferred place of death discussions, advance care planning, symptom management, death/dying discussions or to aid parental decision-making ([table 2](#)).

There was no overall agreement among either CCPs or PCPs on whether referrals of children with complex cardiac conditions to palliative care were untimely.

### Attitudes towards palliative care and its key components

There were significant differences between CCPs and PCPs not only in their views and attitudes towards palliative care, but also

**Table 2** Reasons for referral to palliative care

Cited reason	Reported by cardiac care providers	Reported by palliative care providers
Preferred place of death discussions	73/74 (98.6%)	51/72 (70.8%)
Advance care planning discussions	70/74 (94.6%)	42/72 (58.3%)
Symptom management	67/74 (90.5%)	45/72 (62.5%)
To discuss death/dying issues with parents	64/74 (86.5%)	37/72 (51.4%)
Assist with parental decision-making	58/74 (78.4%)	33/72 (45.8%)
To discuss anticipated outcomes	54/74 (73%)	32/72 (44.4%)
Interprofessional conflict	47/74 (63.5%)	21/72 (29.2%)
Do-not-attempt resuscitation discussions	43/74 (58.1%)	32/72 (44.4%)

in its key components and impact on parental hope (figure 1). Both CCPs and PCPs reported that palliative care extended beyond the end of life phase (statement 1), the last weeks of life (statement 2) and could be instituted even when management had not yet been decided (statement 5).

While CCPs disagreed among themselves on the acceptability (statement 3) and impact of introducing palliative care on parental hope (statement 4), they agreed on its value as a support to clinicians (statement 9), when there was disagreement among professionals (statement 6) and in managing symptoms (statement 8).

### Confidence in delivering key components of palliative care

Both CCPs and PCPs reported confidence in: discussing ‘goals of care’ (statement 1) and concerns over ‘death and dying’ (statement 3), ‘caring for a deteriorating child over hours to days’ (statement 4) and ‘providing care during the ‘end of life period’ (statement 8). PCPs were more confident than CCPs in the first three of these activities and also more confident in discussions around preferred place of death (statement 6). There was, however, no difference in confidence between PCPs and CCPs in providing care during the ‘end of life period’ (statement 8) (figure 2).

While PCPs reported confidence in discussing resuscitation with 16-year-old children, CCPs did not. Neither PCPs nor CCPs expressed confidence discussing resuscitation with 12-year-old children ( $p < 0.001$  for both).

Both CCPs and PCPs reported similarly low levels of confidence in prognostication ( $p = 0.27$ ). For both, this was the area of lowest reported confidence.

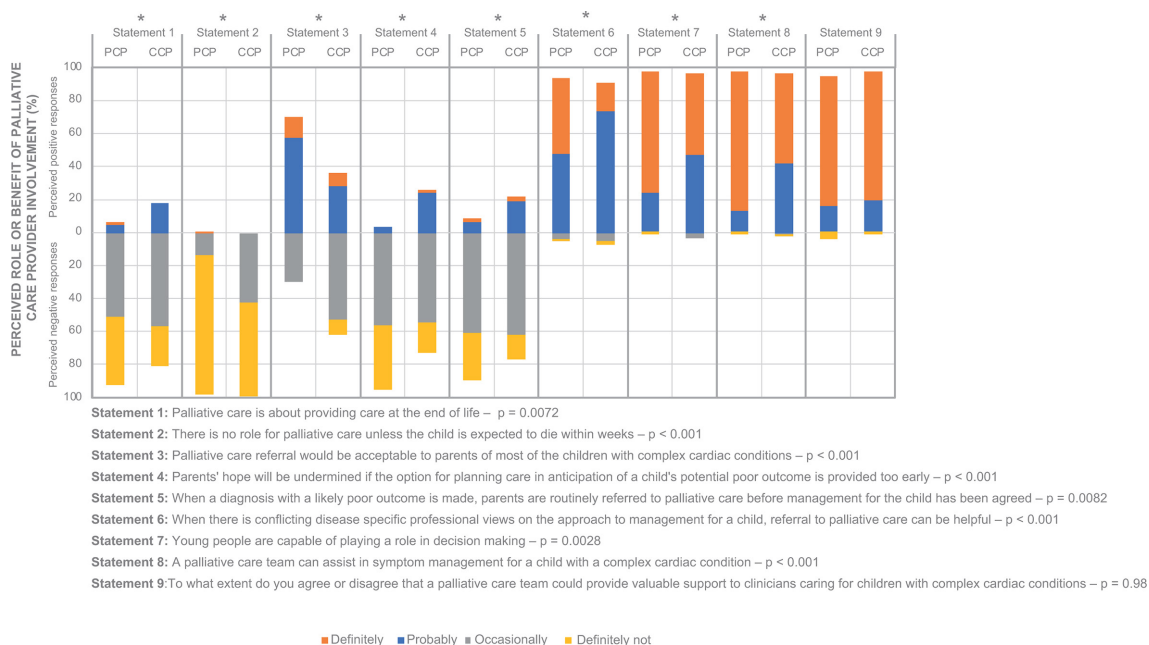
### Palliative care involvement in clinical scenarios

CCPs and PCPs agreed that children with: no further surgical options (scenario 1), an antenatal diagnosis of single ventricle disease (scenario 2), a ventricular assist device in situ (scenario 3), a comorbid genetic condition (scenario 4), symptomatic cardiac failure from myocardial dysfunction (scenario 5) and those awaiting cardiac transplantation (scenario 11) should be referred to palliative care (figure 3). Of these, PCPs were more likely than CCPs to agree that babies diagnosed antenatally with single ventricle disease (scenario 2) and those with a comorbid genetic condition (scenario 4) should be referred to palliative care.

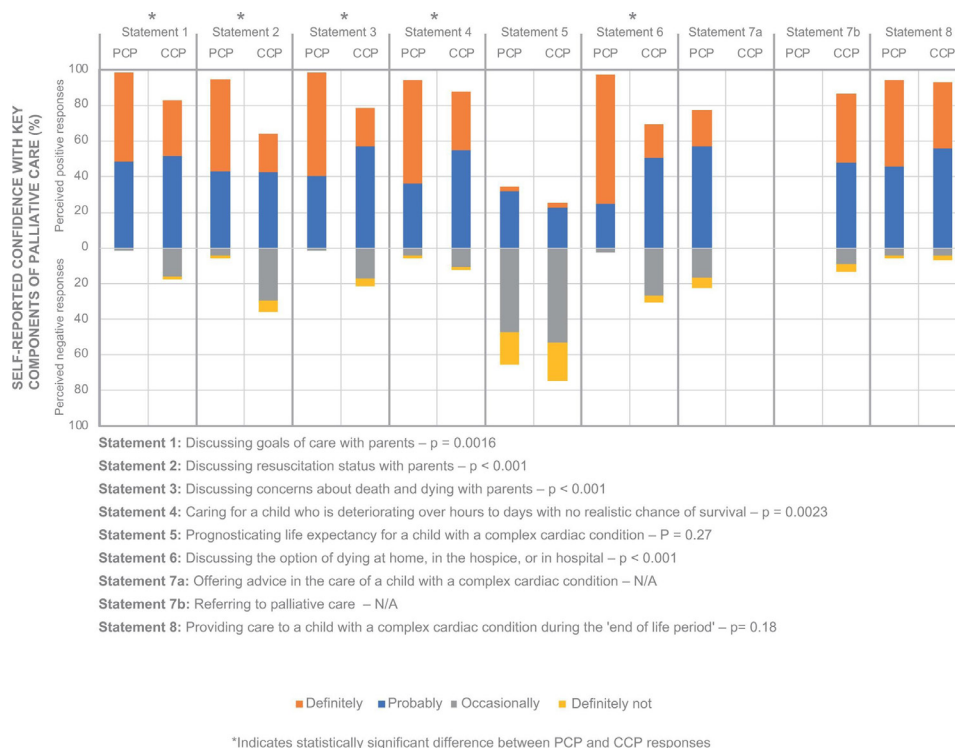
While there was lack of agreement among CCPs about whether a child with a prolonged intensive care unit stay (scenario 6), neonate with single ventricle disease proceeding to surgery (scenario 10) and those with lack of professional consensus over the treatment plan (scenario 12) should be referred to palliative care, there was no significant overall difference in these responses between PCPs and CCPs.

Although neither group agreed on palliative care involvement for a planned ventricular assist device (scenario 9), implantable cardiac defibrillator (scenario 8) or for a child receiving extra-corporeal membrane oxygenation (scenario 7), CCPs were more likely to agree with the statement that palliative care should be involved for a child being planned for a ventricular assist device.

PCPs were ranked by both CCPs and PCPs as the choice for assistance after a colleague in the same team, but before a clinical ethics panel in cases of disagreement about resuscitation status, or in cases where withdrawing artificial nutrition/hydration, further cardiac surgery, or tracheostomy insertion and long-term ventilation were being considered.



**Figure 1** Attitudes towards palliative care. CCP, cardiac care professional; PCP, palliative care professional.



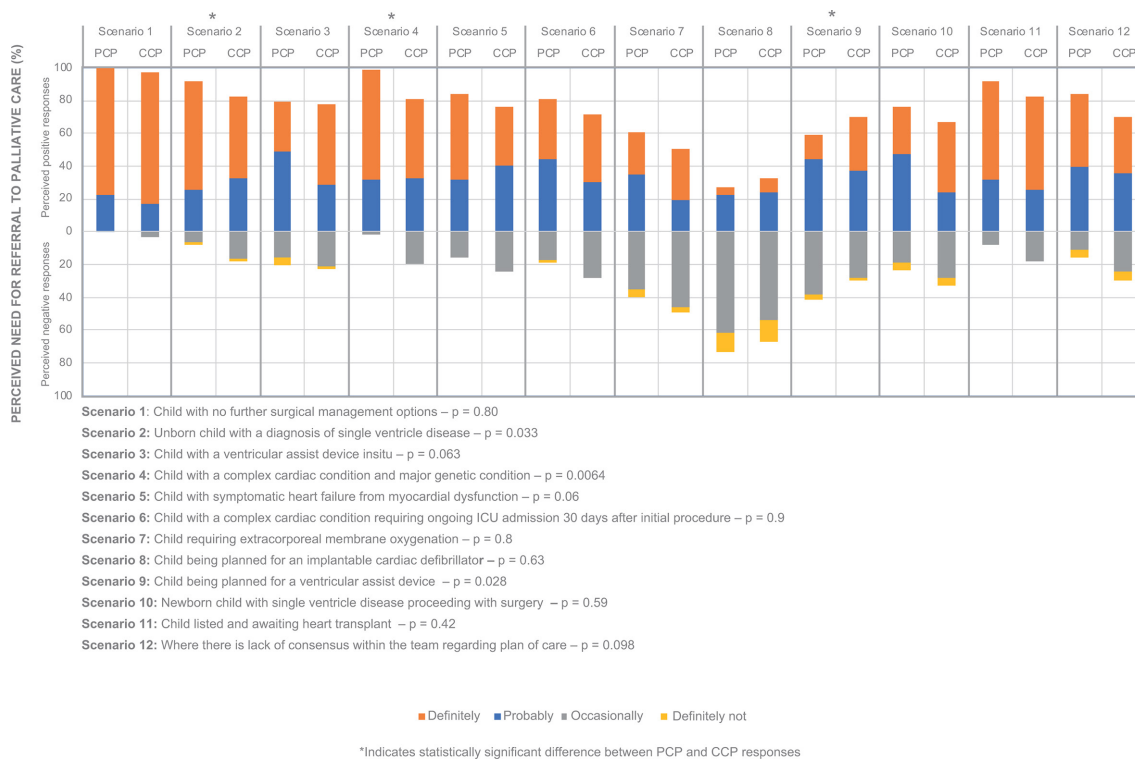
**Figure 2** Self-reported confidence in delivering key components of palliative care. CCP, cardiac care professional; N/A, not applicable; PCP, palliative care professional.

**Qualitative analysis**

One-hundred and thirty-seven participants (69 of 91 (75.8%) CCPs; 68 of 86 (79%) PCPs) responded to one or more of the open-ended questions; elaborating on their responses to closed-ended questions regarding attitudes to palliative care, confidence in delivering palliative care and when to refer to PCPs.

Additional information not directly touched on in closed-ended questions included: (1) foregrounding quality of life as an indicator for referral; (2) nature of uncertainty and (3) management of parental hope.

While the term 'quality of life' did not appear in the survey (as meaning is variously interpreted<sup>29</sup>), it was raised by both



**Figure 3** Referral practices related to clinical scenarios. CCP, cardiac care professional; ICU, intensive care unit; PCP, palliative care professional.

CCPs and PCPs as an indicator for referral. For example, referring a child *'ideally when [the child] becomes unstable/quality of life is in question'* (CCP, <1-year experience in current role) or *'at the point of diagnosis ... selling all the positive benefits about focusing on having the best life they can rather than approaching it from the end of life care perspective'* (PCP, 7–9 years of experience in current role).

The nature of uncertainty, particularly around surgery, as an indicator for referral to PCPs, was made more explicit in some responses. For example, in CCPs' statements, while there was support for earlier referral, this was defined as when there were *'no further surgical options'* (CCP, 4–6 years of experience in current role) or *'at the point where treatment has failed'* (CCP, >10 years of experience in current role). PCPs remarked on surgery, but more broadly, including risk and the future as in *'when there is uncertainty about the future or [the child is] facing potentially risky surgery'* (PCP, 1–3 years of experience in current role).

Management of hope also figured in CCPs' comments on referral, which should occur *'as early as possible PROVIDING it is managed carefully with the families and that they are helped to see that this is not saying that we are giving up on their child'* (CCP, 4–6 years of experience in current role).

## DISCUSSION

This study revealed significant agreement between CCPs and PCPs on when children with complex cardiac conditions should be referred to PCPs. There was also strong agreement on the roles of PCPs and their contributions to enhancing care. Given this strong support for referral to PCPs and specific indicators for doing so both in this study and others,<sup>4 8 10–13 24 30–32</sup> why do we repeatedly see calls for earlier and greater referral to palliative care not only for children with complex cardiac conditions, but also for other life-threatening conditions?<sup>14 19 24 31 33–35</sup>

We would suggest the solution to this conundrum lies in reframing the question from: *How can we achieve earlier and greater referral to palliative care?* to: *How can we achieve the benefits of palliative care in the face of conscious and unconscious individual and institutional barriers?* These barriers often establish a dichotomy between 'fixing' the child versus supporting best quality of life. Previous studies indicate that while parents prefer palliative care principles and practices integrated into their child's treatment,<sup>36–39</sup> they do not necessarily want to receive those services from PCPs. They prefer to receive them from their treating teams.

Building on CCPs and PCPs' shared vision of which children would benefit, we would recommend integrated models of care for children with complex cardiac conditions such as that described by Moynihan *et al*<sup>40</sup> enhanced by PCPs providing an educative and supportive role to CCPs in such aspects of care as advance care planning. We hypothesise that with such an approach, CCPs will gain greater confidence in delivering essential components of palliative care as well as better management in face of deterioration and death. Moreover, parents will be able to have advance care planning conversations with those they want to—the treating team.<sup>36 37</sup> Not inconsequentially such an approach may also enhance clinicians' skills in other areas of practice including talking with parents and children about less charged issues, as well as reducing the risk of overwhelming the availability of palliative care resources.

## Strengths and weaknesses/limitations of the study

This study was robust, involving senior multidisciplinary professionals matched in seniority in both groups, capturing

perspectives of those with valuable experience. Reflecting the field, the survey also included all potential providers of palliative care. As a national survey, the findings extend beyond practices and perspectives within a single institution.

To reach the greatest number of professionals, participants were recruited through national organisations and snowball sampling was encouraged. However, given this strategy, we cannot report the response rate. We recognise the potential biases within the sample, based on gender, given significant differences in medical and nursing respondents, limited number of cardiac surgical respondents and those from non-medical/nursing backgrounds. We agree that professionals who are interested in this area may have been more likely to participate, and note that those with different attitudes towards palliative care may not be represented in our sample. We acknowledge the implications that this lack of inclusion might have on planning service model innovations, and as such, hope future research will capture the variety of perspectives of individuals within institutions. In addition, we encourage further study of interpretations of quality of life, content of advance care planning discussions and how these might fit within cardiac treatment plans.

Aware of the inherent limitations in exploring perspectives through a survey, we used 4-point Likert scales, removing the neutral option, ensuring a more definitive response. The disparity in overall number of responses to closed-ended questions with multiple options and no requirement to rank responses was addressed through open-ended questions which provided opportunities for elaboration and clarification of closed responses. Finally, the survey was unique in inclusion of clinical scenarios which identified how CCPs applied their perspectives in practice and provided opportunities for PCPs to specify which children they could offer the most help with.

## CONCLUSION

This study provides evidence-based guidance for integration and delivery of palliative care to children with no further surgical management options, comorbid genetic disorders, an antenatal diagnosis of a single ventricle, ventricular device in situ, symptomatic heart failure from myocardial dysfunction and those listed and awaiting heart transplantation. Further research and training are needed to address confidence levels in cardiac care professionals in delivering components of palliative care as well as clarification of professional roles and parent preferences in delivery of family-centred care for children with complex cardiac conditions.

**Twitter** Sidharth Vemuri @SidVemuri, Ashleigh E Butler @AshleighEButler, Jo Wray @dr\_jowray and Myra Bluebond-Langner @LDCentre1

**Acknowledgements** The authors acknowledge the Paediatric Intensive Care Society Study Group, the British Congenital Cardiac Association, the Congenital Cardiac Nurses Association, the Association for Paediatric Palliative Medicine and the Children's Palliative Care Special Interest Group of the Royal College of Nursing for assistance in recruitment.

**Contributors** All authors made a substantial contribution to: the conception or design of the work; and the acquisition, analysis, or interpretation of data for the work; and drafting the work or revising it critically for important intellectual content; and final approval of the version to be published; and agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

**Funding** SV's post was supported by the Great Ormond Street Hospital NHS Foundation Trust, and is currently supported by the Victorian Paediatric Palliative Care Programme through the Royal Children's Hospital, Melbourne. AEB's post at the Louis Dundas Centre for Children's Palliative Care is supported by Great Ormond Street Children's Charity (513947). KB and JW are supported by the Great Ormond Street Hospital NHS Foundation Trust. MB-L's post is supported by funding from The

True Colours Trust (511830). This research was also supported by the NIHR Great Ormond Street Hospital Biomedical Research Centre.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplemental information. Requests for non-identifiable statistical and qualitative data files should be addressed to the corresponding author; dissemination must comply with the European Union General Data Protection Regulation.

**Supplemental material** This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

#### ORCID iDs

Sidharth Vermuri <http://orcid.org/0000-0003-1900-4557>

Ashleigh E Butler <http://orcid.org/0000-0001-8682-2854>

Katherine Brown <http://orcid.org/0000-0002-0729-4959>

Jo Wray <http://orcid.org/0000-0002-4769-121>

Myra Bluebond-Langner <http://orcid.org/0000-0001-9281-5431>

#### REFERENCES

- Knowles RL, Ridout D, Crowe S, *et al*. Ethnic and socioeconomic variation in incidence of congenital heart defects. *Arch Dis Child* 2017;102:496–502.
- Knowles RL, Bull C, Wren C, *et al*. Mortality with congenital heart defects in England and Wales, 1959–2009: exploring technological change through period and birth cohort analysis. *Arch Dis Child* 2012;97:861–5.
- Brown KL, Crowe S, Franklin R, *et al*. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. *Open Heart* 2015;2:e000157.
- Blume ED, Balkin EM, Aiyagari R, *et al*. Parental perspectives on suffering and quality of life at end-of-life in children with advanced heart disease: an exploratory study\*. *Pediatr Crit Care Med* 2014;15:336–42.
- Morell E, Wolfe J, Scheurer M, *et al*. Patterns of care at end of life in children with advanced heart disease. *Arch Pediatr Adolesc Med* 2012;166:745–8.
- Crowe S, Ridout DA, Knowles R, *et al*. Death and emergency readmission of infants discharged after interventions for congenital heart disease: a national study of 7643 infants to inform service improvement. *J Am Heart Assoc* 2016;5:e003369.
- Rogers L, Pagel C, Sullivan ID, *et al*. Interventional treatments and risk factors in patients born with hypoplastic left heart syndrome in England and Wales from 2000 to 2015. *Heart* 2018;104:1500–7.
- Marcus KL, Balkin EM, Al-Sayegh H, *et al*. Patterns and outcomes of care in children with advanced heart disease receiving palliative care consultation. *J Pain Symptom Manage* 2018;55:351–8.
- Brown KL, Utens E, Marino BS. The ten things you need to know about long-term outcomes following paediatric cardiac surgery. *Intensive Care Med* 2018;44:918–21.
- Mazwi ML, Henner N, Kirsch R. The role of palliative care in critical congenital heart disease. *Semin Perinatol* 2017;41:128–32.
- Bertaud S, Lloyd DFA, Laddie J, *et al*. The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease. *Arch Dis Child* 2016;101:984–7.
- Kaufman BD, Cohen HJ. Palliative care in pediatric heart failure and transplantation. *Curr Opin Pediatr* 2019;31:611–6.
- Wan A, Weingarten K, Rapoport A. Palliative care?! But this child's not dying: the Burgeoning partnership between pediatric cardiology and palliative care. *Can J Cardiol* 2020;36:1041–9.
- Hancock HS, Pituch K, Uzark K, *et al*. A randomised trial of early palliative care for maternal stress in infants prenatally diagnosed with single-ventricle heart disease. *Cardiol Young* 2018;28:561–70.
- Gans D, Kominski GF, Roby DH, *et al*. Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions. *Policy Brief UCLA Cent Health Policy Res* 2012;PB2012-3:1–8.
- Groh G, Vyhnalek B, Feddersen B, *et al*. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. *J Palliat Med* 2013;16:848–56.
- Schmidt P, Otto M, Hechler T, *et al*. Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer? *J Palliat Med* 2013;16:1034–9.
- Vollenbroich R, Duroux A, Grasser M, *et al*. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med* 2012;15:294–300.
- Wolfe J, Friebert S, Hilden J. Caring for children with advanced cancer integrating palliative care. *Pediatr Clin North Am* 2002;49:1043–62.
- Sidgwick P, Fraser J, Fortune P-M, *et al*. Parallel planning and the paediatric critical care patient. *Arch Dis Child* 2019;104:994–7.
- The National Institute for Cardiovascular Outcomes Research. The National Institute for cardiovascular outcomes research: national congenital health disease audit (NCHDA) 2020 summary report (2018/19 data), 2020. Available: <https://nicor.org.uk/national-cardiac-audit-programme/congenital-heart-disease-in-children-and-adults-congenital-audit/> [Accessed 12 Jan 2021].
- Together for Short Lives. Together for Short Lives' report to NHS England: A national overview of the readiness of the children's palliative care sector to implement the NICE End of Life Care for Infants, Children and Young People: Planning and Management Guide, 2017. Available: <https://www.togetherforshortlives.org.uk/resource/implementation-of-nice-guideline-national-audit/> [Accessed 12 Jan 2021].
- Rychik J. What does palliative care mean in prenatal diagnosis of congenital heart disease? *World J Pediatr Congenit Heart Surg* 2013;4:80–4.
- Balkin EM, Kirkpatrick JN, Kaufman B, *et al*. Pediatric cardiology provider attitudes about palliative care: a multicenter survey study. *Pediatr Cardiol* 2017;38:1324–31.
- Twamley K, Craig F, Kelly P, *et al*. Underlying barriers to referral to paediatric palliative care services: knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the United Kingdom. *J Child Health Care* 2014;18:19–30.
- SurveyMonkey Inc. San Mateo, California, USA. Available: [www.surveymonkey.com](http://www.surveymonkey.com)
- IBM Corp. *IBM SPSS statistics for windows, version 25.0*. Armonk, NY: IBM Corp, 2017.
- NVivo qualitative data analysis. QSR International Pty Ltd, Version 11, 2015.
- Beecham E, Langner R, Hargrave D, *et al*. Children's and parents' conceptualization of quality of life in children with brain tumors: a Meta-Ethnographic exploration. *Qual Health Res* 2019;29:55–68.
- Davis JAM, Bass A, Humphrey L, *et al*. Early integration of palliative care in families of children with single ventricle congenital heart defects: a quality improvement project to enhance family support. *Pediatr Cardiol* 2020;41:114–22.
- Balkin EM, Sleeper LA, Kirkpatrick JN, *et al*. Physician perspectives on palliative care for children with advanced heart disease: a comparison between pediatric cardiology and palliative care physicians. *J Palliat Med* 2018;21:773–9.
- Goloff N, Joy BF. A part of the team: the changing role of palliative care in congenital heart disease. *Prog Pediatr Cardiol* 2018;48:59–62.
- Durall A, Zurakowski D, Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. *Pediatrics* 2012;129:e975–82.
- Dalberg T, Jacob-Files E, Carney PA, *et al*. Pediatric oncology providers' perceptions of barriers and facilitators to early integration of pediatric palliative care. *Pediatr Blood Cancer* 2013;60:1875–81.
- Levine DR, Mandrell BN, Sykes A, *et al*. Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology. *JAMA Oncol* 2017;3:1214–20.
- DeCoursey DD, Silverman M, Oladunjoye A, *et al*. Advance care planning and Parent-Reported end-of-life outcomes in children, adolescents, and young adults with complex chronic conditions. *Crit Care Med* 2019;47:101–8.
- Mack JW, Hilden JM, Watterson J, *et al*. Parent and physician perspectives on quality of care at the end of life in children with cancer. *J Clin Oncol* 2005;23:9155–61.
- Bluebond-Langner M, Belasco JB, Goldman A, *et al*. Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *J Clin Oncol* 2007;25:2414–9.
- Wolfe J, Hammel JF, Edwards KE, *et al*. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol* 2008;26:1717–23.
- Moynihan KM, Snaman JM, Kaye EC, *et al*. Integration of pediatric palliative care into cardiac intensive care: a Champion-Based model. *Pediatrics* 2019;144:e20190160.

## 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](mailto: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 <b>parents</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing resuscitation status with <b>parents</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing concerns about death and dying with <b>parents</b>	<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 <b>no further surgical management options</b> technically possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Unborn child</b> with an antenatal diagnosis of a single ventricle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a <b>ventricular assist device in-situ</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition and a <b>major genetic disorder</b> (excluding trisomy 21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with <b>symptomatic heart failure</b> from myocardial dysfunction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition who requires <b>ongoing ICU/HDU admission</b> 30-days after their initial procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child requiring <b>ECMO</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being <b>planned for an implantable cardiac defibrillator</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being <b>planned for a ventricular assist device</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Newborn child</b> with a single ventricle proceeding with surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child listed and awaiting <b>heart transplantation</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where there is <b>lack of professional consensus</b> 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
<p><b>Scenario:</b> Child with a single ventricle, post first-stage palliative surgery, who has recurrent cardiac arrests</p> <p><b>Issue:</b> The family want full resuscitation but the treating clinician wants to limit ongoing resuscitation interventions</p>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<p><b>Scenario:</b> 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</p> <p><b>Issue:</b> The family want to pursue surgical repair but the treating clinician feels this should not be offered</p>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<p><b>Scenario:</b> Child who has remained in the intensive care for six months with CPAP dependence, following palliative cardiac surgery</p> <p><b>Issue:</b> The family want a tracheostomy inserted but the treating clinician does not feel it should be offered</p>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<p><b>Scenario:</b> Child with trisomy 21, failure to thrive and corrected congenital heart disease</p> <p><b>Issue:</b> 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</p>	<input type="text"/>	<input type="text"/>	<input type="text"/>

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](mailto: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.**
- **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?

- |                             |                              |
|-----------------------------|------------------------------|
| <input type="radio"/> <1%   | <input type="radio"/> 25-50% |
| <input type="radio"/> 1-5%  | <input type="radio"/> >50%   |
| <input type="radio"/> 5-25% | <input type="radio"/> 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 <b>parents</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing resuscitation status with <b>parents</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing concerns about death and dying with <b>parents</b>	<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)   |  |

\* 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 <b>no further surgical management options</b> technically possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Unborn child</b> with an antenatal diagnosis of a single-ventricle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a <b>ventricular assist device in-situ</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition and a <b>major genetic disorder</b> (excluding trisomy 21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with <b>symptomatic heart failure</b> from myocardial dysfunction	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child with a complex cardiac condition who requires <b>ongoing ICU/HDU admission</b> 30-days after their initial procedure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child requiring <b>ECMO</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being <b>planned for an implantable cardiac defibrillator</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child being <b>planned for a ventricular assist device</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>Newborn child</b> with a single-ventricle proceeding with surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child listed and awaiting <b>heart transplantation</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where there is <b>lack of professional consensus</b> 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.**



## Supplementary Data File - 2

**Palliative care for children with complex cardiac conditions: survey results***Raw data*

Q13. Do you think there are barriers to discussing goals of care?

	Yes	No
<b>Palliative Care Provider (PCP)</b>	58/78 (74.4%)	20/78 (25.6%)
<b>Cardiac Care Provider (CCP)</b>	73/89 (82%)	16/89 (18%)

Q15. To what extent do you agree or disagree with the following?

a) Palliative care is primarily about providing care at the end of life

	Strongly disagree	Disagree	Agree	Strongly agree
<b>PCP</b>	30/72 (41.7%)	37/72 (51.4%)	4/72 (5.6%)	1/72 (1.4%)
<b>CCP</b>	18/75 (24%)	43/75 (57.3%)	14/75 (18.7%)	0

b) There is no role for palliative care involvement unless the child is expected to die within weeks

	Strongly disagree	Disagree	Agree	Strongly agree
<b>PCP</b>	61/72 (84.7%)	10/72 (13.9%)	0	1/72 (1.4%)
<b>CCP</b>	43/75 (57.3%)	32/75 (42.7%)	0	0

c) Palliative care referral would be acceptable to the parents of most of the children with complex cardiac conditions.

	Strongly disagree	Disagree	Agree	Strongly agree
<b>PCP</b>	0	21/72 (29.2%)	42/72 (58.3%)	9/72 (12.5%)
<b>CCP</b>	7/75 (9.3%)	40/75 (53.3%)	22/75 (29.3%)	6/75 (8%)

d) Parents' hope will be undermined if the option for planning care and treatment in anticipation of a child's potential poor outcome is provided too early

	Strongly disagree	Disagree	Agree	Strongly agree
<b>PCP</b>	28/72 (38.9%)	41/72 (56.9%)	3/72 (4.2%)	0
<b>CCP</b>	14/75 (18.7%)	41/75 (54.7%)	19/75 (25.3%)	1/75 (1.3%)

## Supplementary Data File - 2

- e) When a diagnosis with a likely poor outcome is made, parents are routinely referred to palliative care before management for the child has been agreed

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
<b>PCP</b>	21/72 (29.2%)	44/72 (61.1%)	5/72 (6.9%)	2/72 (2.8%)
<b>CCP</b>	11/75 (14.5%)	47/75 (62.7%)	15/75 (20%)	2/75 (2.7%)

- f) When there are conflicting disease specific professional views on the approach to management for a child, a referral to palliative care can be helpful

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
<b>PCP</b>	1/72 (1.4%)	3/72 (4.2%)	35/72 (48.6%)	33/72 (45.8%)
<b>CCP</b>	2/75 (2.7%)	4/75 (5.3%)	56/75 (74.7%)	13/75 (17.3%)

- g) Young people are capable of playing a role in decision making

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
<b>PCP</b>	1/72 (1.4%)	0	18/72 (25%)	53/72 (73.6%)
<b>CCP</b>	0	2/75 (2.7%)	36/75 (48%)	37/75 (49.3%)

- h) A palliative care team can assist in symptom management for a child with a complex cardiac condition.

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
<b>PCP</b>	1/72 (1.4%)	0	10/72 (13.9%)	61/72 (84.7%)
<b>CCP</b>	1/75 (1.3%)	1/75 (1.3%)	32/75 (42.7%)	41/75 (54.7%)

Q16. In general, how confident do you feel with the following clinical activities?

- a) Discussing GoC with parents

	<b>Very confident</b>	<b>Confident</b>	<b>Not confident</b>	<b>Not at all confident</b>
<b>PCP</b>	36/72 (50%)	35/72 (48.6%)	1/72 (1.4%)	0
<b>CCP</b>	23/75 (30.7%)	39/75 (52%)	12/75 (16%)	1/75 (1.5%)

- b) Discussing resuscitation status with parents

	<b>Very confident</b>	<b>Confident</b>	<b>Not confident</b>	<b>Not at all confident</b>
<b>PCP</b>	37/72 (51.4%)	31/72 (43.1%)	3/72 (4.2%)	1/72 (1.4%)
<b>CCP</b>	16/75 (21.3%)	32/75 (42.7%)	22/75 (29.3%)	5/75 (6.7%)

## Supplementary Data File - 2

## c) Discussing concerns about death and dying with parents

	Very confident	Confident	Not confident	Not at all confident
PCP	42/72 (58.3%)	29/72 (40.3%)	1/72 (1.4%)	0
CCP	16/75 (21.3%)	43/75 (57.3%)	13/75 (17.3%)	3/75 (4%)

## d) Caring for a child who is deteriorating over hours to days with no realistic chance of survival

	Very confident	Confident	Not confident	Not at all confident
PCP	42/72 (58.3%)	26/72 (36.1%)	3/72 (4.2%)	1/72 (1.4%)
CCP	25/75 (33.3%)	41/75 (54.7%)	8/75 (10.7%)	1/75 (1.3%)

## e) Prognosticating life expectancy for a child with a complex cardiac condition

	Very confident	Confident	Not confident	Not at all confident
PCP	2/72 (2.8%)	23/72 (31.9%)	34/72 (47.2%)	13/72 (18.1%)
CCP	2/75 (2.7%)	17/75 (22.7%)	40/75 (53.3%)	16/75 (21.3%)

## f) Discussing the option of dying at home, in the hospice, or at hospital

	Very confident	Confident	Not confident	Not at all confident
PCP	52/72 (72.2%)	18/72 (25%)	2/72 (2.8%)	0
CCP	14/75 (18.7%)	38/75 (50.7%)	20/75 (26.7%)	3/75 (4%)

## g) Offering advice in the care of a child with a complex cardiac condition

	Very confident	Confident	Not confident	Not at all confident
PCP	15/72 (20.8%)	41/72 (56.9%)	12/72 (16.7%)	4/72 (5.6%)
CCP				

## Referring to PCT

	Very confident	Confident	Not confident	Not at all confident
PCP				
CCP	29/75 (38.7%)	36/75 (48%)	7/75 (9.3%)	3/75 (4%)

## h) Providing care to a child with a complex cardiac condition during the 'end of life care period'

	Very confident	Confident	Not confident	Not at all confident

## Supplementary Data File - 2

<b>PCP</b>	35/72 (48.6%)	33/72 (45.8%)	3/72 (4.2%)	1/72 (1.4%)
<b>CCP</b>	28/75 (37.3%)	42/75 (56%)	3/75 (4%)	2/75 (2.7%)

Q17. Please select if you are confident discussing the following with a young person:

a) Aged 12 years

**GOC**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	64/69	5/69
<b>CCP</b>	52/57	5/57

**Resus**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	42/68	27/69
<b>CCP</b>	18/57	39/57

**Death and dying**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	57/69	12/69
<b>CCP</b>	33/57	24/57

b) Aged 16 years

**GOC**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	68/71	3/71
<b>CCP</b>	61/63	2/63

**Resus**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	57/71	14/71
<b>CCP</b>	36/63	27/63

**Death and dying**

	<b>Yes</b>	<b>No</b>
<b>PCP</b>	63/71	8/71
<b>CCP</b>	45/63	18/63

Q18. 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.

## Supplementary Data File - 2

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly agree</b>
<b>PCP</b>	3/72 (4.2%)	0	12/72 (16.7%)	57/72 (79.2%)
<b>CCP</b>	1/74 (1.4%)	0	15/74 (20.3%)	58/74 (78.4%)

Q19. In the last year, how often have you received referrals from clinicians for children with complex cardiac conditions (PC) or how often have you made referrals to the PC team (cardiologists)?

	<b>Never</b>	<b>Rarely</b>	<b>Occasionally</b>	<b>Regularly</b>
<b>PCP</b>	5/72 (6.9%)	11/72 (15.3%)	39/72 (54.2%)	17/72 (23.6%)
<b>CCP</b>	9/74 (12.2%)	20/74 (27%)	27/74 (36.5%)	18/75 (24.3%)

Q20. Why have children with complex cardiac conditions been referred to you?

<b>PCP</b>		<b>CCP</b>	
PPoD Discussions	51/72 (70.8%)	PPoD Discussions	73/74 (98.6%)
Symptom management	45/72 (62.5%)	Parental care planning	70/74 (94.6%)
Parental care planning	42/72 (58.3%)	Symptom management	67/74 (90.5%)
Discuss death/dying issues	37/72 (51.4%)	Discuss death/dying issues	64/74 (86.5%)
Parental decision making	33/72 (45.8%)	Parental decision making	58/74 (78.4%)
Outcome discussions	32/72 (44.4%)	Outcome discussions	54/74 (73%)
DNAR discussions	32/72 (44.4%)	Interprofessional conflict	47/74 (63.5%)

Q21. In general, do you feel that children were referred to palliative care

	<b>At the appropriate time</b>	<b>Too early</b>	<b>Too late</b>	<b>N/A</b>
<b>PCP</b>	30/72 (41.7%)	0	42/72 (58.3%)	0
<b>CCP</b>	21/73 (28.8%)	0	46/73 (63%)	6/73 (8.2%)

Q23. Do you think children in the following clinical scenarios should be referred to palliative care?

a) Child where there are no further surgical management options possible

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	49/63 (77.8%)	14/63 (22.2%)	0	0
<b>CCP</b>	53/66 (80.3%)	11/66 (16.7%)	2/66 (3%)	0

b) Unborn child with an antenatal diagnosis of a single ventricle

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
--	-------------------	-----------------	---------------------	-----------------------

## Supplementary Data File - 2

<b>PCP</b>	42/63 (66.7%)	16/63 (25.4%)	4/63 (6.3%)	1/63 (1.6%)
<b>CCP</b>	33/67 (49.3%)	22/67 (32.8%)	11/67 (16.4%)	1/67 (1.5%)

## c) Child with a VAD insitu

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	19/63 (30.2%)	31/63 (49.2%)	10/63 (15.9%)	3/63 (4.8%)
<b>CCP</b>	33/67 (49.3%)	19/67 (28.4%)	14/67 (20.9%)	1/67 (1.5%)

## d) Child with a complex cardiac disorder and a major genetic condition

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	42/63 (66.7%)	20/63 (31.7%)	1/63 (1.6%)	0
<b>CCP</b>	32/67 (47.8%)	22/67 (32.8%)	13/67 (19.4%)	0

## e) Child with symptomatic heart failure from myocardial dysfunction

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	33/63 (52.4%)	20/63 (31.7%)	10/63 (15.9%)	0
<b>CCP</b>	24/67 (35.8%)	27/67 (40.3%)	16/67 (23.9%)	0

## f) Child with a complex cardiac condition who requires ongoing ICU admission 30 days after their initial procedure

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	23/63 (36.5%)	28/63 (44.4%)	11/63 (17.5%)	1/63 (1.6%)
<b>CCP</b>	28/67 (41.8%)	20/67 (29.9%)	19/67 (28.4%)	0

## g) Child requiring ECMO

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	16/63 (25.4%)	22/63 (34.9%)	22/63 (34.9%)	3/63 (4.8%)
<b>CCP</b>	21/67 (31.3%)	13/67 (19.4%)	31/67 (46.3%)	2/67 (3%)

## h) Child being planned for ICD

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	3/63 (4.8%)	14/63 (22.2%)	39/63 (61.9%)	7/63 (11.1%)
<b>CCP</b>	6/67 (9%)	16/67 (23.9%)	36/67 (53.7%)	9/67 (13.4%)

## i) Child being planned for VAD

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	9/63 (14.3%)	28/63 (44.4%)	24/63 (38.1%)	2/63 (3.2%)
<b>CCP</b>	22/67 (32.8%)	25/67 (37.3%)	19/67 (28.4%)	1/67 (1.5%)

## Supplementary Data File - 2

## j) Newborn child with a single ventricle preceding with surgery

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	18/63 (28.6%)	30/63 (47.6%)	12/63 (19%)	3/63 (4.8%)
<b>CCP</b>	29/67 (43.3%)	16/67 (23.9%)	19/67 (28.4%)	3/67 (4.5%)

## k) Child listed and awaiting heart transplant

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	38/63 (60.3%)	20/63 (31.7%)	5/63 (7.9%)	0
<b>CCP</b>	38/67 (56.7%)	17/67 (25.4%)	12/67 (17.9%)	0

## l) Where there is a lack of professional consensus within the treating team regarding the plan of care

	<b>Definitely</b>	<b>Probably</b>	<b>Occasionally</b>	<b>Definitely not</b>
<b>PCP</b>	28/63 (44.4%)	25/63 (39.7%)	7/63 (11.1%)	3/63 (4.8%)
<b>CCP</b>	23/67 (34.3%)	24/67 (35.8%)	16/67 (23.9%)	4/67 (6%)

Q24. In the following clinical scenarios, please select and rank the most useful sources of additional support for the treating clinician

## a) Resuscitation

## COLLEAGUE

	<b>1st</b>	<b>2nd</b>	<b>3rd</b>	<b>N/A</b>
<b>PCP</b>	34/63 (54%)	17/63 (27%)	11/63 (17.5%)	1/63 (1.6%)
<b>CCP</b>	62/67 (92.5%)	1/67 (1.5%)	2/67 (3%)	2/67 (3%)

## CLINICAL ETHICS PANEL

	<b>1st</b>	<b>2nd</b>	<b>3rd</b>	<b>N/A</b>
<b>PCP</b>	10/63 (15.9%)	14/63 (22.2%)	37/63 (58.7%)	2/63 (3.2%)
<b>CCP</b>	2/67 (3%)	10/67 (14.9%)	47/67 (70.1%)	8/67 (11.9%)

## PCT

	<b>1st</b>	<b>2nd</b>	<b>3rd</b>	<b>N/A</b>
<b>PCP</b>	22/63 (34.9%)	31/63 (49.2%)	10/63 (15.9%)	0
<b>CCP</b>	5/67 (7.5%)	51/67 (76.1%)	4/67 (6%)	7/67 (10.4%)

## b) Surgery

## COLLEAGUE

	<b>1st</b>	<b>2nd</b>	<b>3rd</b>	<b>N/A</b>
<b>PCP</b>	44/63 (69.8%)	7/63 (11.1%)	12/63 (19%)	0
<b>CCP</b>	61/67 (91%)	2/67 (3%)	2/67 (3%)	2/67 (3%)

## Supplementary Data File - 2

## CLINICAL ETHICS PANEL

	1st	2nd	3rd	N/A
<b>PCP</b>	9/63 (14.3%)	12/63 (19%)	40/63 (63.5%)	2/63 (3.2%)
<b>CCP</b>	3/67 (4.5%)	12/67 (17.9%)	44/67 (65.7%)	8/67 (11.9%)

## PCT

	1st	2nd	3rd	N/A
<b>PCP</b>	14/63 (22.2%)	40/63 (63.5%)	8/63 (12.7%)	1/63 (1.6%)
<b>CCP</b>	7/67 (10.4%)	46/67 (68.7%)	9/67 (13.4%)	5/67 (7.5%)

## c) Tracheostomy

## COLLEAGUE

	1st	2nd	3rd	N/A
<b>PCP</b>	36/63 (57.1%)	11/63 (17.5%)	16/63 (25.4%)	0
<b>CCP</b>	55/67 (82.1%)	9/67 (13.4%)	1/67 (1.5%)	2/67 (3%)

## CLINICAL ETHICS PANEL

	1st	2nd	3rd	N/A
<b>PCP</b>	10/63 (15.9%)	19/63 (30.2%)	28/63 (44.4%)	6/63 (9.5%)
<b>CCP</b>	6/67 (9%)	8/67 (11.9%)	45/67 (67.2%)	8/67 (11.9%)

## PCT

	1st	2nd	3rd	N/A
<b>PCP</b>	19/63 (30.2%)	33/63 (52.4%)	10/63 (15.9%)	1/63 (1.6%)
<b>CCP</b>	9/67 (13.4%)	43/67 (64.2%)	7/67 (10.4%)	8/37 (11.9%)

## d) Nutrition/Hydration challenge

## COLLEAGUE

	1st	2nd	3rd	N/A
<b>PCP</b>	36/63 (57.1%)	16/63 (25.4%)	10/63 (15.9%)	1/63 (1.6%)
<b>CCP</b>	61/67 (91%)	3/67 (4.5%)	0	3/67 (4.5%)

## CLINICAL ETHICS PANEL

	1st	2nd	3rd	N/A
<b>PCP</b>	12/63 (19%)	22/63 (34.9%)	25/63 (39.7%)	4/63 (6.3%)
<b>CCP</b>	3/37 (4.5%)	18/67 (26.9%)	25/67 (37.3%)	21/67 (31.3%)



## Supplementary Data File - 2

PCT

	<b>1st</b>	<b>2nd</b>	<b>3rd</b>	<b>N/A</b>
<b>PCP</b>	18/63 (28.6%)	23/63 (36.5%)	16/63 (25.4%)	6/63 (9.5%)
<b>CCP</b>	5/67 (7.5%)	28/67 (41.8%)	11/67 (16.4%)	23/67 (34.3%)