

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
Palliative Care Provider (PCP)	58/78 (74.4%)	20/78 (25.6%)
Cardiac Care Provider (CCP)	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
PCP	30/72 (41.7%)	37/72 (51.4%)	4/72 (5.6%)	1/72 (1.4%)
CCP	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
PCP	61/72 (84.7%)	10/72 (13.9%)	0	1/72 (1.4%)
CCP	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
PCP	0	21/72 (29.2%)	42/72 (58.3%)	9/72 (12.5%)
CCP	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
PCP	28/72 (38.9%)	41/72 (56.9%)	3/72 (4.2%)	0
CCP	14/75 (18.7%)	41/75 (54.7%)	19/75 (25.3%)	1/75 (1.3%)

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- 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

	Strongly disagree	Disagree	Agree	Strongly agree
PCP	21/72 (29.2%)	44/72 (61.1%)	5/72 (6.9%)	2/72 (2.8%)
CCP	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

	Strongly disagree	Disagree	Agree	Strongly agree
PCP	1/72 (1.4%)	3/72 (4.2%)	35/72 (48.6%)	33/72 (45.8%)
CCP	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

	Strongly disagree	Disagree	Agree	Strongly agree
PCP	1/72 (1.4%)	0	18/72 (25%)	53/72 (73.6%)
CCP	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.

	Strongly disagree	Disagree	Agree	Strongly agree
PCP	1/72 (1.4%)	0	10/72 (13.9%)	61/72 (84.7%)
CCP	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

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

- b) Discussing resuscitation status with parents

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

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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

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PCP	35/72 (48.6%)	33/72 (45.8%)	3/72 (4.2%)	1/72 (1.4%)
CCP	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

	Yes	No
PCP	64/69	5/69
CCP	52/57	5/57

Resus

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

Death and dying

	Yes	No
PCP	57/69	12/69
CCP	33/57	24/57

b) Aged 16 years

GOC

	Yes	No
PCP	68/71	3/71
CCP	61/63	2/63

Resus

	Yes	No
PCP	57/71	14/71
CCP	36/63	27/63

Death and dying

	Yes	No
PCP	63/71	8/71
CCP	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.

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	Strongly disagree	Disagree	Agree	Strongly agree
PCP	3/72 (4.2%)	0	12/72 (16.7%)	57/72 (79.2%)
CCP	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)?

	Never	Rarely	Occasionally	Regularly
PCP	5/72 (6.9%)	11/72 (15.3%)	39/72 (54.2%)	17/72 (23.6%)
CCP	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?

PCP		CCP	
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

	At the appropriate time	Too early	Too late	N/A
PCP	30/72 (41.7%)	0	42/72 (58.3%)	0
CCP	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

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

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

	Definitely	Probably	Occasionally	Definitely not
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PCP	42/63 (66.7%)	16/63 (25.4%)	4/63 (6.3%)	1/63 (1.6%)
CCP	33/67 (49.3%)	22/67 (32.8%)	11/67 (16.4%)	1/67 (1.5%)

c) Child with a VAD insitu

	Definitely	Probably	Occasionally	Definitely not
PCP	19/63 (30.2%)	31/63 (49.2%)	10/63 (15.9%)	3/63 (4.8%)
CCP	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

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

e) Child with symptomatic heart failure from myocardial dysfunction

	Definitely	Probably	Occasionally	Definitely not
PCP	33/63 (52.4%)	20/63 (31.7%)	10/63 (15.9%)	0
CCP	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

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

g) Child requiring ECMO

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

h) Child being planned for ICD

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

i) Child being planned for VAD

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

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j) Newborn child with a single ventricle preceding with surgery

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

k) Child listed and awaiting heart transplant

	Definitely	Probably	Occasionally	Definitely not
PCP	38/63 (60.3%)	20/63 (31.7%)	5/63 (7.9%)	0
CCP	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

	Definitely	Probably	Occasionally	Definitely not
PCP	28/63 (44.4%)	25/63 (39.7%)	7/63 (11.1%)	3/63 (4.8%)
CCP	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

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

CLINICAL ETHICS PANEL

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

PCT

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

b) Surgery

COLLEAGUE

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

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CLINICAL ETHICS PANEL

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

PCT

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

c) Tracheostomy

COLLEAGUE

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

CLINICAL ETHICS PANEL

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

PCT

	1st	2nd	3rd	N/A
PCP	19/63 (30.2%)	33/63 (52.4%)	10/63 (15.9%)	1/63 (1.6%)
CCP	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
PCP	36/63 (57.1%)	16/63 (25.4%)	10/63 (15.9%)	1/63 (1.6%)
CCP	61/67 (91%)	3/67 (4.5%)	0	3/67 (4.5%)

CLINICAL ETHICS PANEL

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

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PCT

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