

# Palliative Care Survey: Perceptions of and Involvement with Heart Failure

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# Survey by questionnaire of all Specialist Palliative Care Providers in England

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## Aim

To audit specialist palliative care (SPC) service's knowledge and perceptions of heart failure and involvement with heart failure patients



# Methods

- SPC services identified from Hospice Directory 2004
- Children's and cancer only hospitals excluded
- Letter and questionnaire sent to named consultant / lead clinician
- No reminders sent
- NCPC assisted with data management



# Questions asked

- Does SPC have a role in providing care for patients with severe / end stage heart failure?
- Does your service currently accept patients with heart failure? If not, why not?
- How many patients with heart failure are under your service/s today?
- Do you have heart failure referral criteria?
- Do you have specific treatment guidelines / pathways for heart failure patients?
- Are you aware of any specific palliative care and heart failure initiatives in your area? (teaching / collaboration / models of care...)



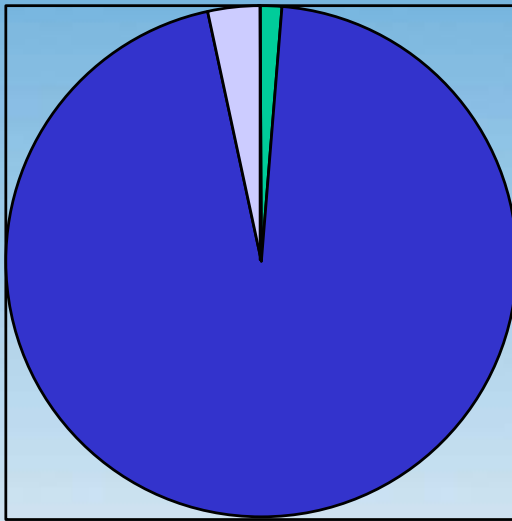
## Results 1

- 452 questionnaires sent out
  - 56 of 452 (12%) sent back combined replies for linked parts of single organisations
  - 1 of 452 sent back 2 replies for non linked / separate services
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- 233 replies; 164 non responders
  - Response rate: 59%



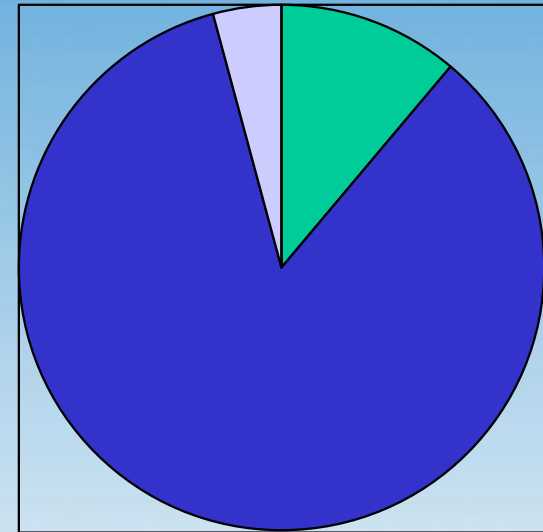
## Results 2

**Does SPC have a role in Providing Care for patients with severe/end stage heart failure?**



1%: No    96%: Yes    not answered

**Do you currently accept patients with heart failure?**



11%: No    85%: Yes    not answered



## Results 3

### Reasons given for accepting no or few heart failure patients

	Heart failure patients not accepted N = 26	Heart failure patients accepted N=15	Acceptance status unknown N = 10	Total N = 51
Lack of resources	20	12	2	34
Implications for staff training	15	7	1	23
Limited bed availability	10	3	2	15
Specific organisational position	4	1	1	6
None / few referred	1	3	1	5
Cardiac professionals can do this	2	1	0	3
Our lack of expertise	1	0	0	1
Other	2	1	0	3
Ethical reasons St Christopher's Hospice	0	0	0	0

## Results 4

### Numbers of patients with heart failure under SPC on day of survey

	No. of specific SPC services Total answers to this question = 225 / 233	Mean no. of patients with heart failure under this service	Range
SPC Inpatient	127	0.4	0 – 20
SPC Home Care	140	1.3	0 – 12
SPC Day Hospice	128	0.8	0 – 39
Hospital Inpatient Support	154	0.4	0 - 4
Hospital Out patient review	110	0.6	0 - 6



## Results 5a

### Referral criteria for specialist palliative care

**15 / 233 (5%) had heart failure specific referral criteria.**

<u>General Referral Criteria</u>	N = 15	%
Specific detail regarding severity and / or complexity of patients' symptom control needs	10	67%
Specific detail regarding severity and / or complexity of patients' other needs (psychological, emotional, spiritual, social)	10	67%
Specific detail regarding severity and / or complexity of families' needs (including high bereavement risk)	9	60%



## Results 5b

### Referral criteria for specialist palliative care

<u>Heart Failure Specific Referral Criteria</u>	N = 15	%
Recurrent hospital admissions with decompensated heart failure, usually without symptomatic improvement	11	73%
Severity of heart failure (NYHA functional classes III and / or IV)	10	67%
Lack of further treatment options making hospital admission inappropriate	9	60%
Specific further medical information (e.g. echocardiogram results, blood results)	2	13%



## Results 6

### Treatment guidelines and pathways

12 / 233 (5%): specific treatment guidelines / pathways in use or being developed:

- 5 : end of life pathways
- 2 : breathlessness management programmes
- 1 : guideline for use of opiates for breathlessness
- 3 : currently writing symptom control guidelines
- 1 : 'Toptips'



## Results 7a

### Models of joint working practices

- 12 / 233 (5%) described specific projects
- 6 submitted documentation about them
  - Referral criteria
  - SPC contact details
  - Symptom control guidelines
  - Service use statistics
  - Joint working practices
- Local service configurations shaped SPC / heart failure initiatives



## Results 7b

### Models of joint working practices: Model 1

- Motivated cardiology consultant and / or specialist nurse *plus*
- Motivated SPC consultant and / or specialist nurse
- Jointly drawn up referral guidelines
- Palliative care consultant assessing patients and referring on to other SPC services
- ‘manageable workload’, ‘appropriate referrals’
- SPC expertise in heart failure steadily increased



## Results 7c

### Models of joint working practices: Model 2

- Motivated cardiology specialist nurses  
*plus*
- Motivated SPC service/s
- Heart failure patient and carer education and support group
- Hospice day centre



## Results 7d

### Models of joint working practices: Model 3

- Community heart failure specialist nurses aiming to be key workers and cover supportive and general palliative care
- Training and ongoing support of these heart failure nurses varied hugely
- One service had SPC CNS spending 1 day / week with community heart failure nurses on ongoing basis

Segal DI, O'Hanlon D, Rahman N, McCarthy DJ, Gibbs JSR. Incorporating palliative care into heart failure management: a new model of care. *Int J Pall Nursing* 2005; 11: 135-136.



## Results 8

# 'Pyramid' of SPC interest in and involvement with heart failure patients

Increasing level of SPC / heart failure engagement

