

Heart Failure Nurses:

A survey of liaison with Specialist
Palliative Care Services

Circulatory & Respiratory
Policy Group

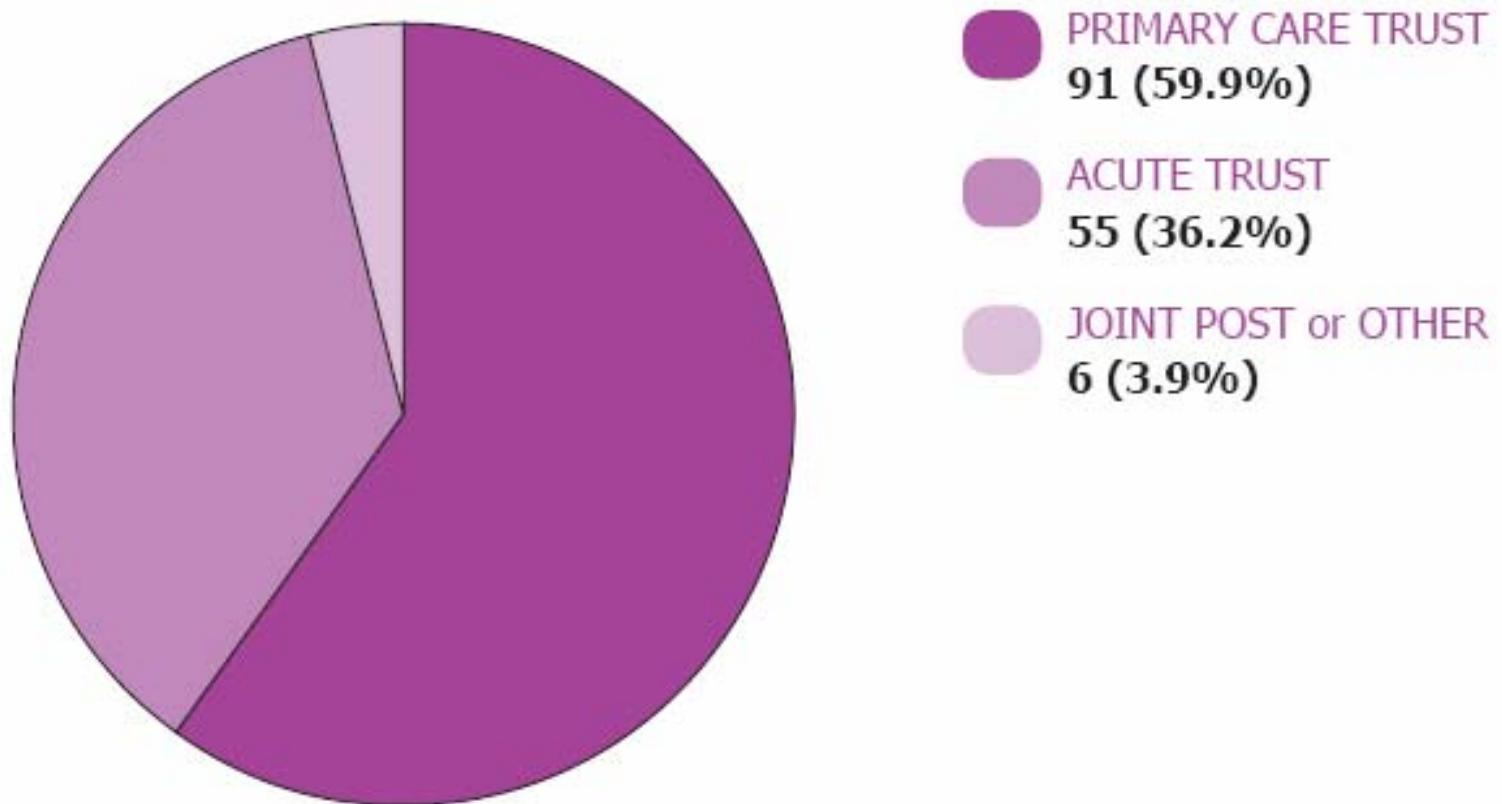
The National Council
for Palliative Care 2006

PURPOSE

- To assess specialist Heart Failure Nurses (HFNs) knowledge of and involvement with Specialist Palliative Care Services (SPC)

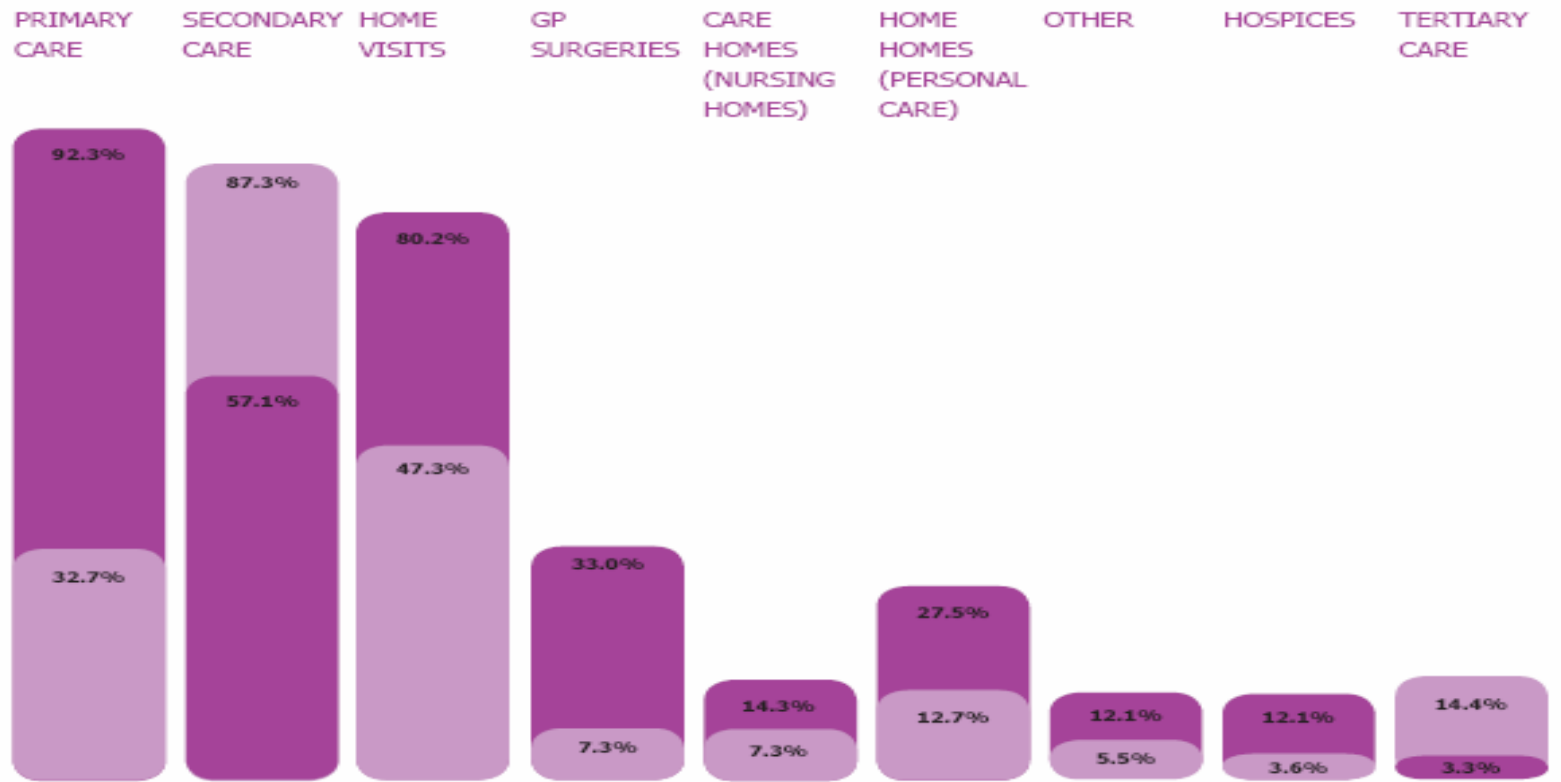
- Questionnaire sent to HFNs via Cardiac Networks
- 152 completed surveys
- Proxy response rate is 62% -- based on British Heart Foundation branded nurses
- Need for workforce mapping exercise (cancer models)

Employed by.....



Work Setting

- HFNs employed by PCTs were more likely to work across primary and secondary services



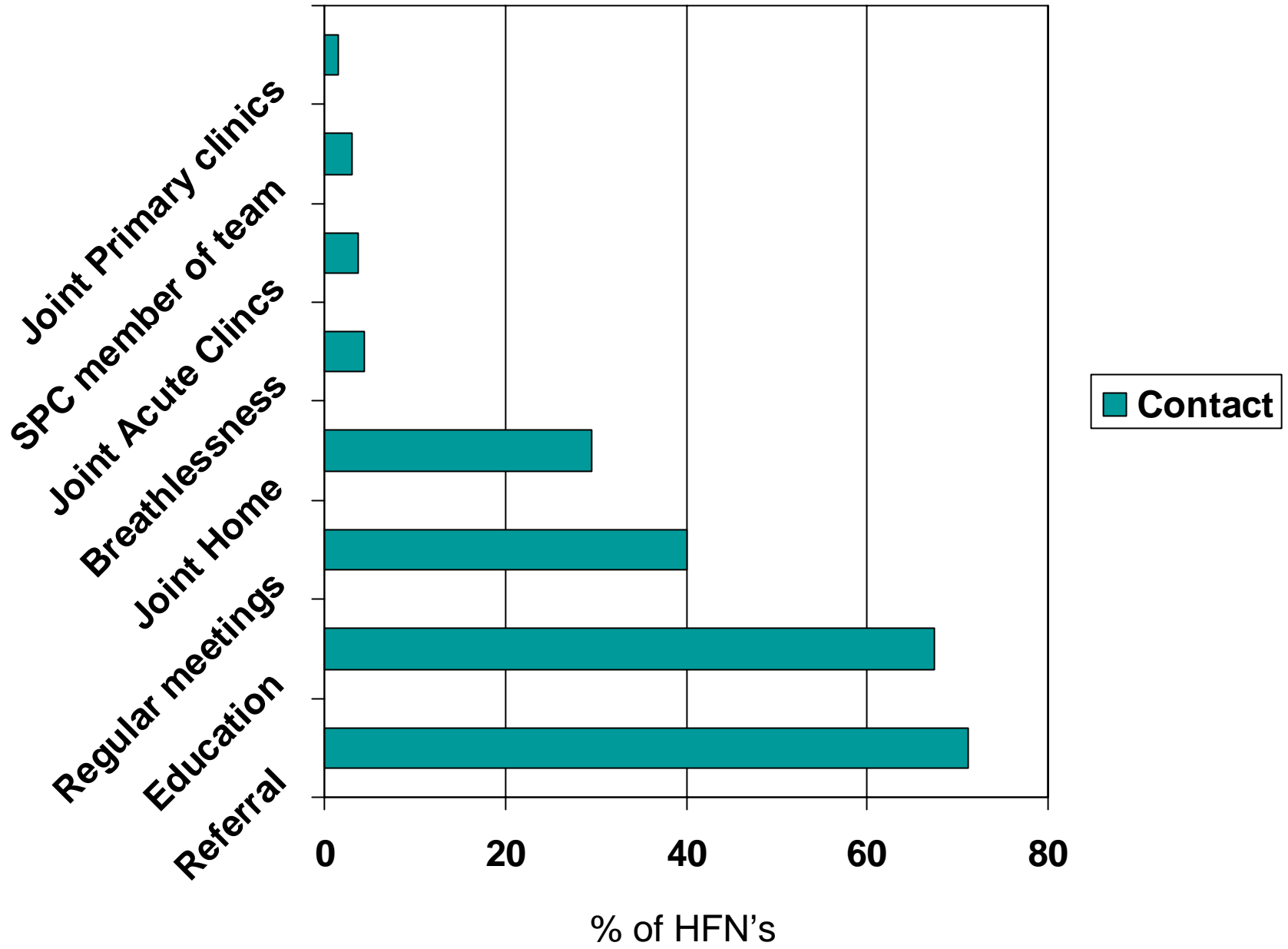
Percentage of total respondents

Employed by PCT (n=91)

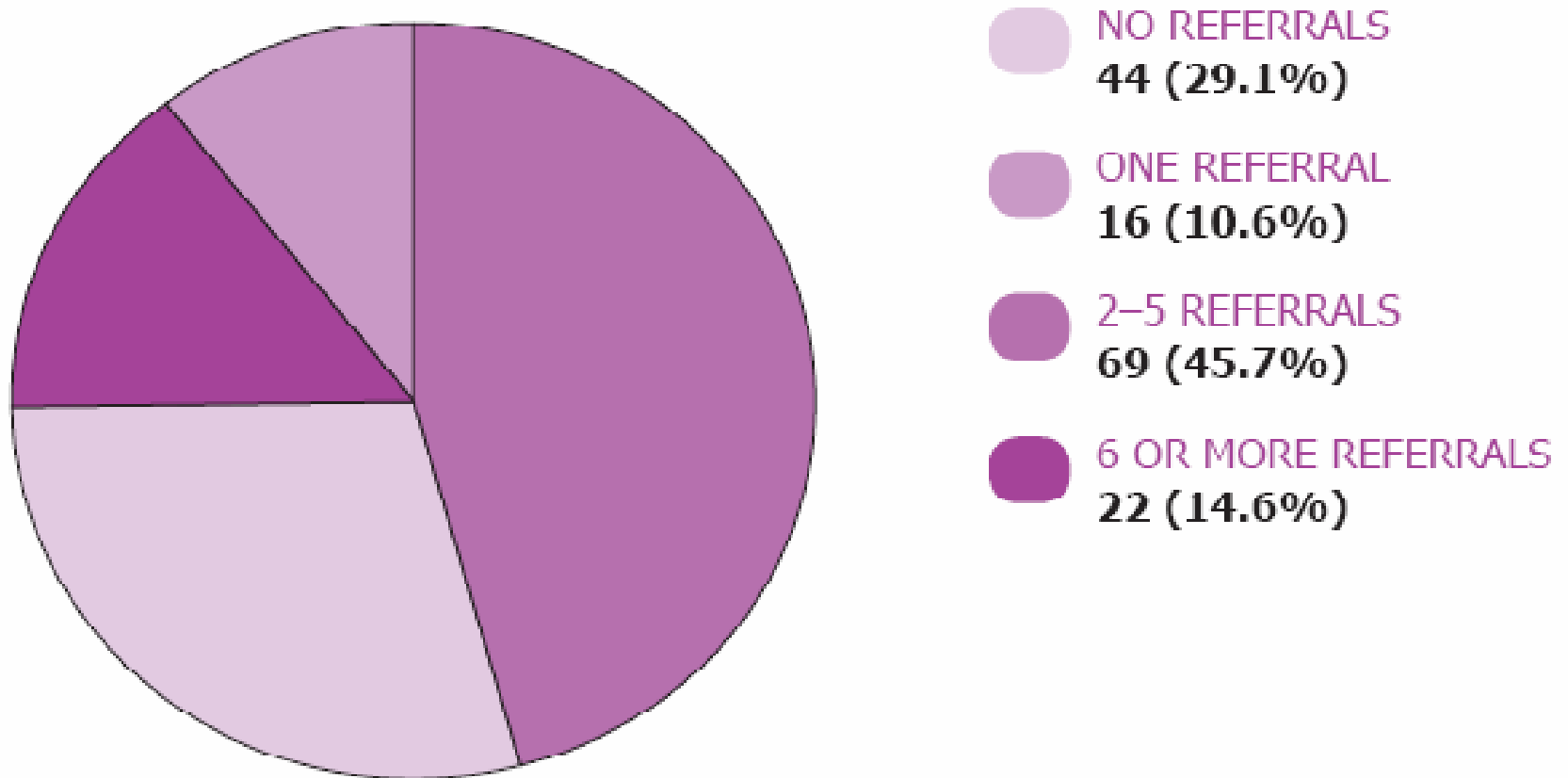
Employed by Acute Trust (n=55)

Contact With SPC

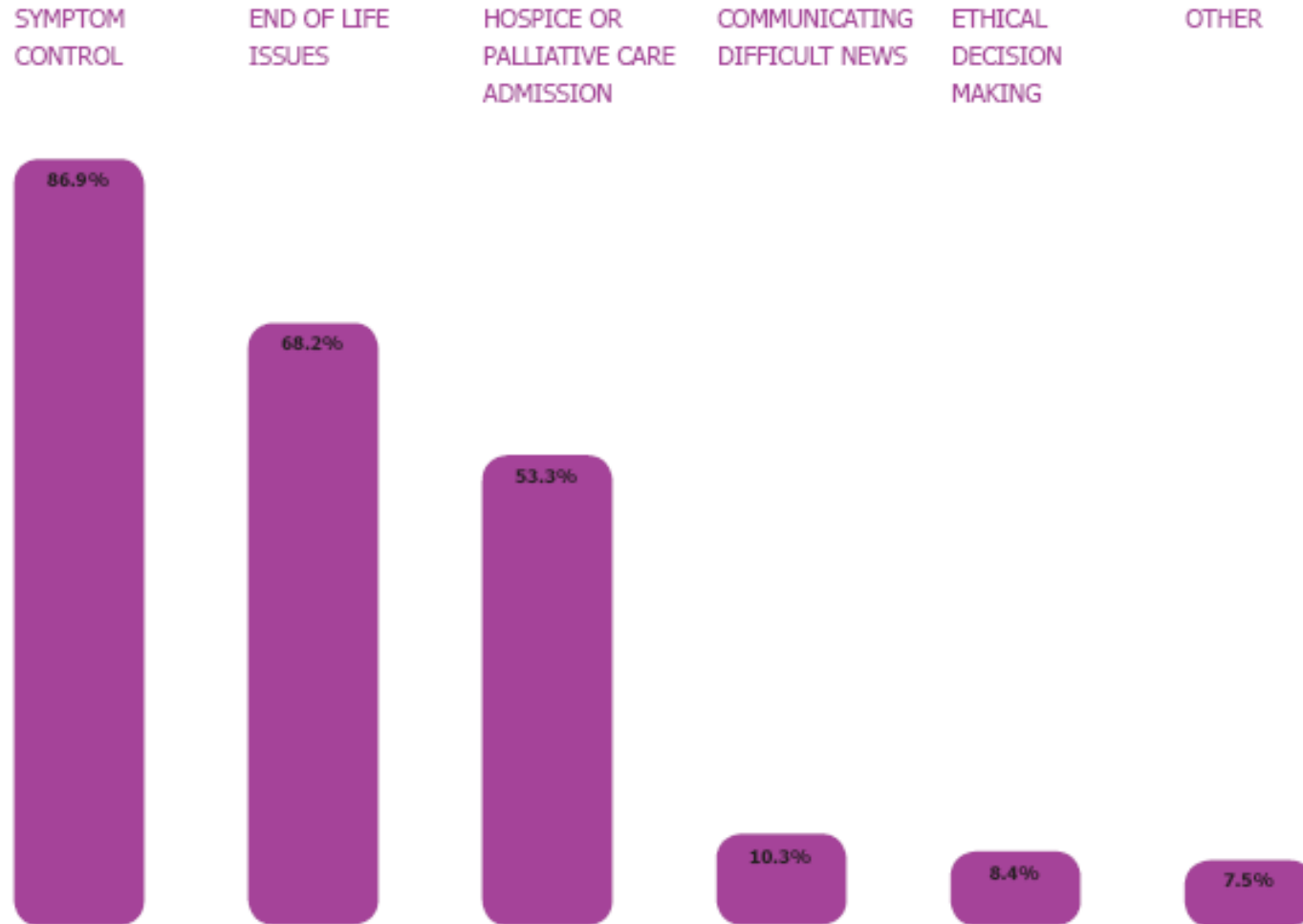
- 99.3% agreement that SPC has role in severe end stage heart failure
- 90% of HFNs had contact with SPC in last 12 month
- 63% had directly referred patients



Number of referrals made in past 12 months by individual HFN's

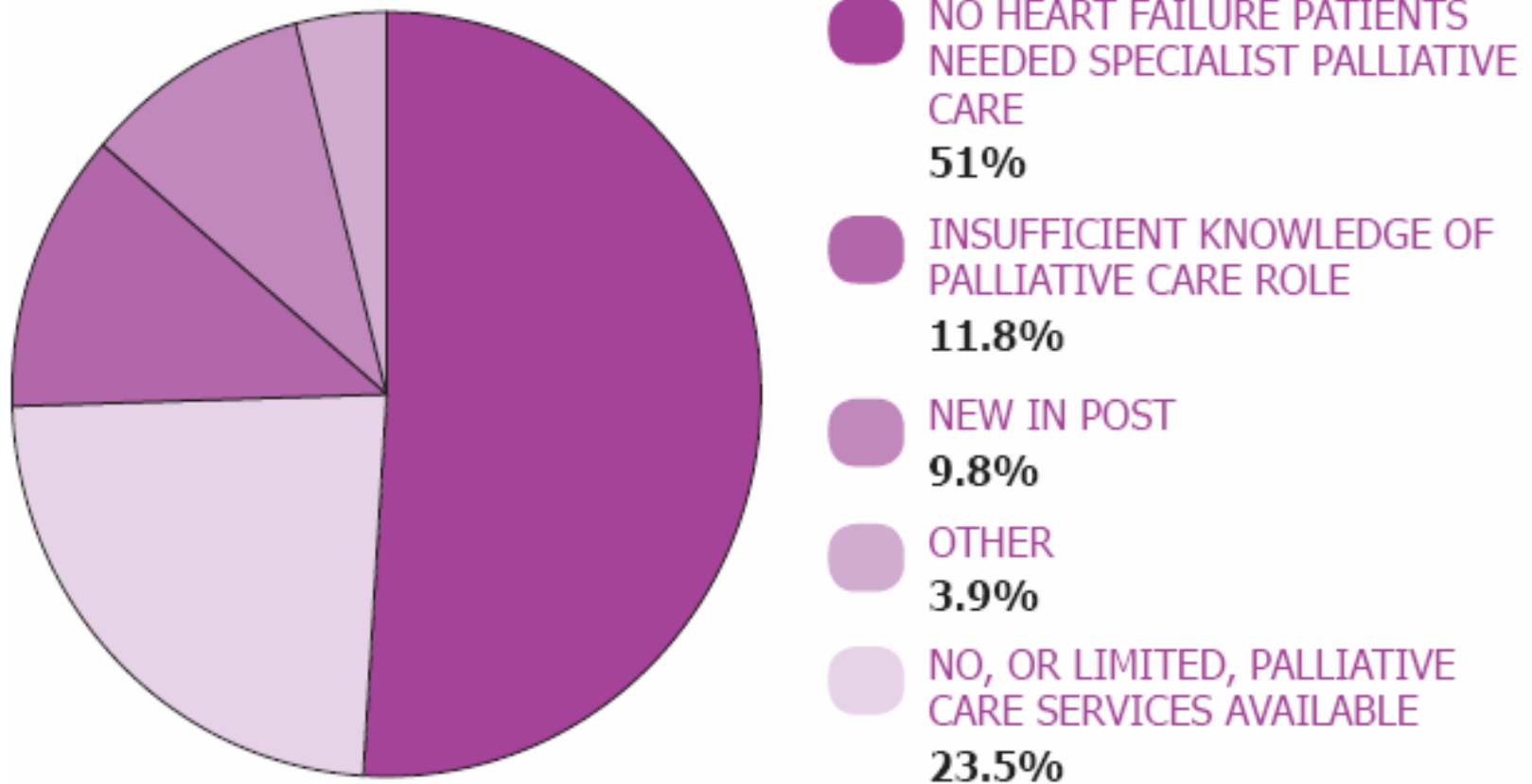


Reasons for Referral



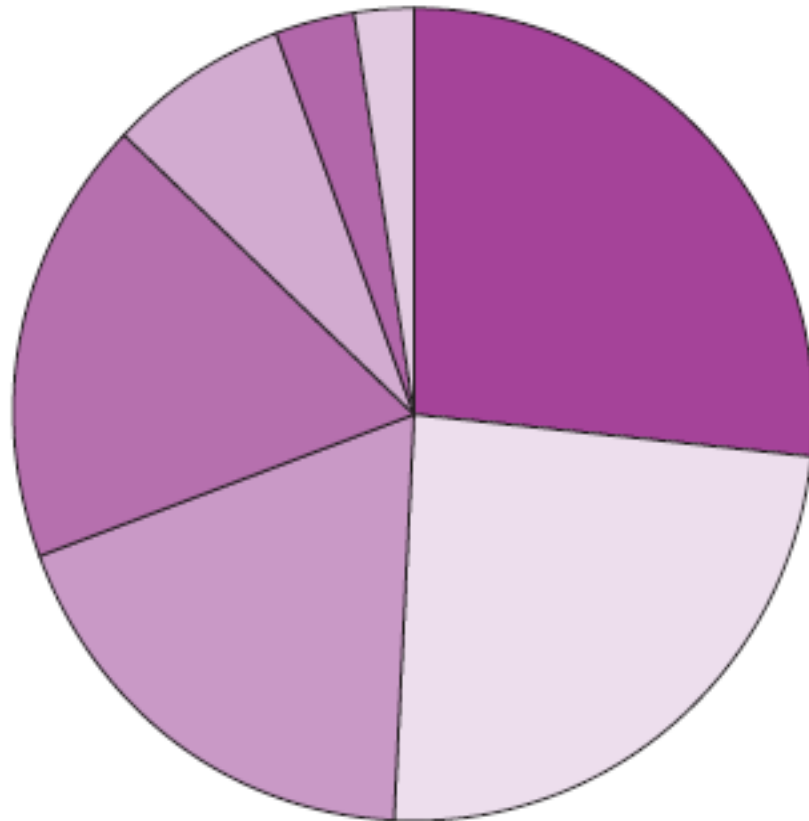
Percentage of respondents giving each reason - more than one reason could be given

Reasons for No Referral



Percentage of respondents making no referrals to SPC

- Over 80% had SPC Training Needs



- SYMPTOM CONTROL
33 (26.6%)
- COMMUNICATION SKILLS AND
BREAKING BAD NEWS
30 (24.1%)
- UNDERSTANDING THE ROLE OF
SPECIALIST PALLIATIVE CARE
23 (18.5%)
- END OF LIFE ISSUES
22 (17.7%)
- BEREAVEMENT COUNSELLING
9 (7.3%)
- OTHER
4 (3.2%)
- ETHICAL DECISION MAKING
3 (2.4%)

Referral Criteria

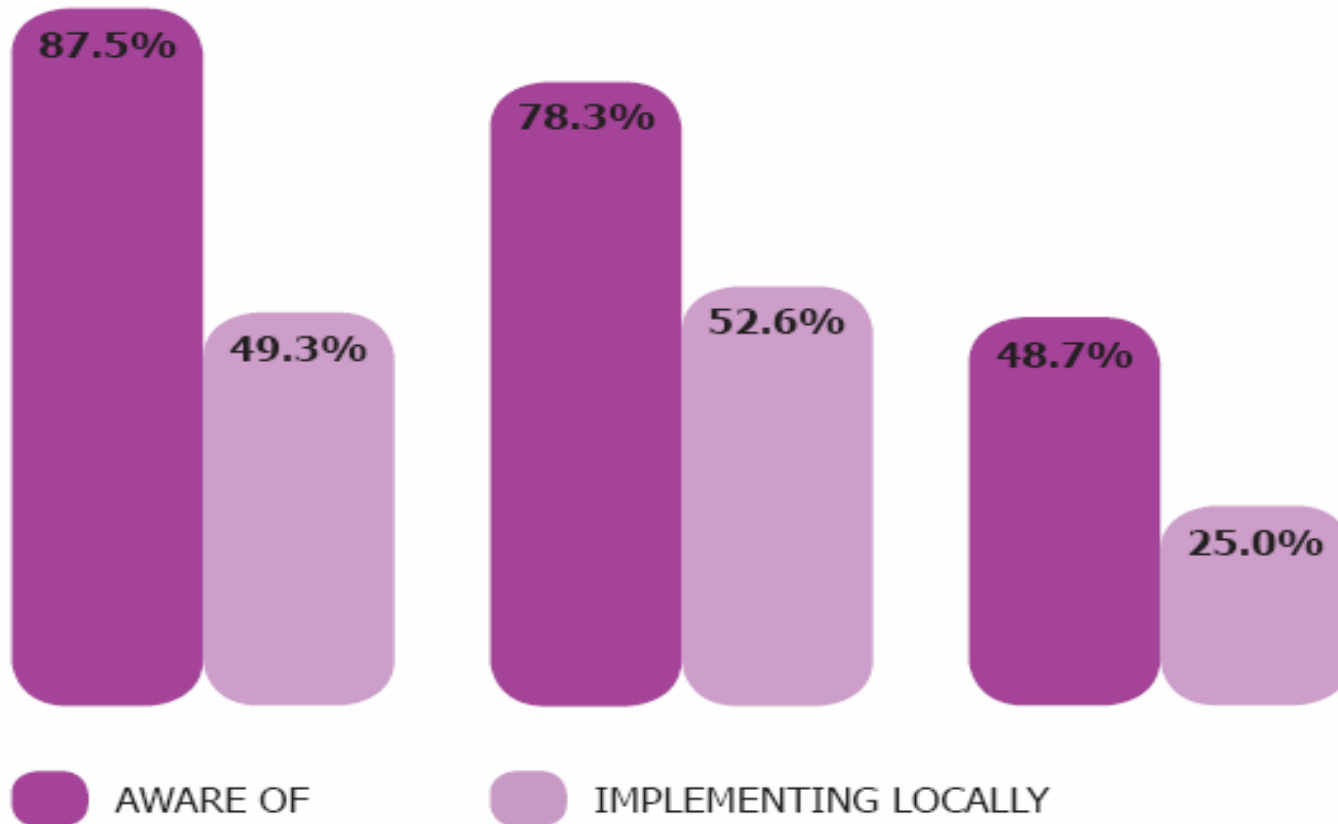
- Most (65.1%) had locally developed referral criteria for SPC
- More than one-quarter (27.1%) had specific referral criterion for heart failure

End of life care national initiatives

LIVERPOOL CARE
FOR THE DYING
PATHWAY

GOLD
STANDARDS
FRAMEWORK

PREFERRED
PLACE OF
CARE



Conclusions

- HFNs employed by PCTs more likely to work across primary and secondary care
- HFNs improving knowledge and linkages with SPC
- Appropriate type of referrals
- Low level of referrals – majority of HFNs make fewer than 5/year
- Regular contact increases referrals
- Orientation and Training needs

Themes from these surveys

- Ring fencing of SPC services excluding patients with heart failure is a significant issue
- Local SPC / HF collaborations appear to be spreading.
 - How do we foster and sustain this, as we struggle the shifting sands of politics and finances?
- Education and support for heart failure nurses in palliative care
 - What can SPC realistically provide to each disease specific area?
 - What should cardiac organisations provide within the specialty?
- Disease specific referral criteria:
 - do they help or hinder?
 - Is ‘triggers for supportive needs reassessment’ a better term?

General Referral Criteria to Specialist Palliative Care (SEL CN)

Most patients will have an advanced, progressive disease, where the focus will have changed from curative to palliative and the prognosis is limited.

Some patients, who have complex specialist needs, can be referred at an earlier stage, from diagnosis onwards.

Patients may be discharged if their condition stabilises.

- A demonstrable need for SPC services must be established. Appropriate reasons for referral may include potential / existing difficulties with the following:
 - Pain and Symptom management
 - Meeting the psycho–social needs of the patients & their family, and / or significant others
 - Terminal care / Dying
- Where possible, the patient, and if not, the carer, should be informed and in agreement with the referral
- Any Health Care Professional can refer to the SPC Team, but acceptance must be with the agreement of the GP or inpatient Consultant

Triggers for Supportive and Palliative Care Needs Reassessment in Heart Failure

Any patient who fits any of the categories below should have their physical, psychological, social and spiritual needs assessed (and acted upon where possible) by their usual health / social carers.

Their potential need for referral to specialist palliative care services should then be assessed against the general SPC referral criteria.

The need for SPC must be discussed with the patient (and carer/s) before referral.

Discussion with SPC colleagues in areas of doubt, urgency or when advice is needed should be encouraged.

- All patients in NYHA functional class IV.

- Symptomatic patients in NYHA class II and III.

- Patients who may benefit from a trial of opioids for dyspnoea.

- Patients who have recurrent hospital admission for decompensated heart failure (e.g. > 4 per annum) despite maximum or optimally tolerated medical treatment, particularly if admission leads to little or no improvement.

- Any circumstance where further hospital admission is not considered to be the best option for the patient.

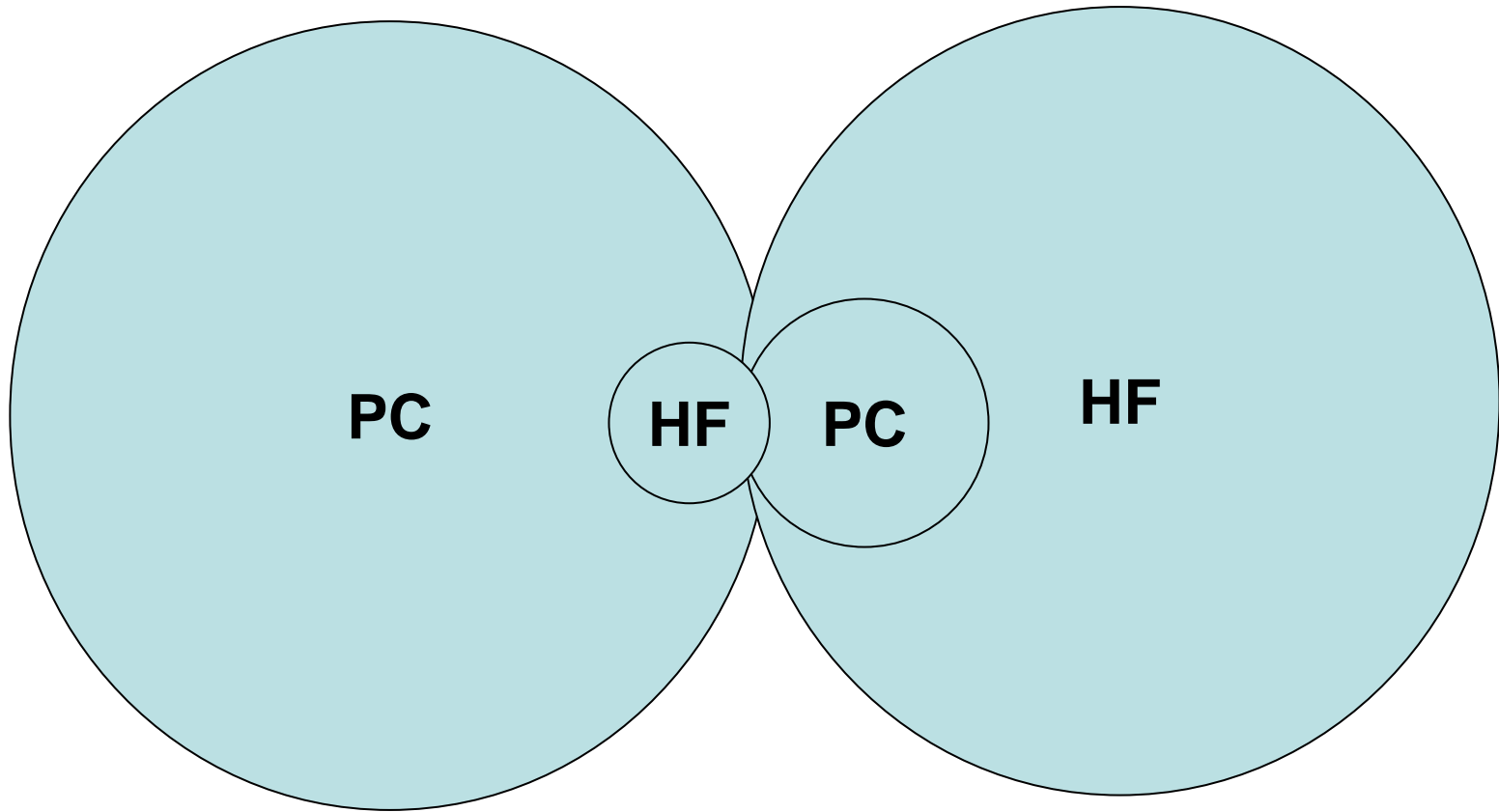
- Cases where there are difficult communication issues (such as coping with uncertainty) or a high bereavement risk.

- Any patient who has had a DS1500 form for attendance allowance under 'special rules' completed or where the Gold Standards Framework has been implemented because of their heart failure.

Questions

- Are HFNs employed by PCTs more likely to work across Health? Across Social Care?
- Does low level of referrals answer concerns that flood gates will open?
- Who's role is training?
- Are specific guidelines for referral preferable?
What might be the impact for HF and SPCN?
Trigger points for contact?
- How can local collaboration be improved?

How do we keep the workload manageable?



The willingness is here but is the capacity?

