Ten reasons to appoint a heart failure specialist nurse (HFSN):

1. Heart failure is common, costly, and impacts greatly on quality of life. HFSNs can work across primary, secondary, and tertiary care by promoting patient information and supporting nurses in other areas of the hospital.

2. It is known that multi-disciplinary team interventions can improve outcomes and reduce hospital readmissions. HFSNs can help to support these interventions, which can lead to improved care for patients.

3. HFSNs can extend knowledge in primary care of how to manage heart failure patients and carers. They can provide education and advice about heart failure, its treatment, and what to do after hospital discharge. They can help identify patients who need further care and coordinate care with other members of the MDT.

4. HFSNs identify patients who may benefit from having access to secretarial support and enhanced staff communication. This can lead to better patient outcomes and improved patient satisfaction.

5. HFSNs improve health-related quality of life in both hospital and community settings. They can help patients manage their condition and improve their quality of life.

6. HFSNs can co-ordinate a shared care approach to end of life care with other members of the MDT. This can help to ensure that patients are managed in a dignified and respectful manner, with appropriate care and support.

7. HFSNs reduce all cause admissions by an average of 35%. This is known to reduce costs of the HFSNs have been deducted. Approximately £1,826 per patient seen is gained after the costs of the HFSNs have been deducted.

8. HFSNs can work across primary, secondary, and tertiary care by promoting patient information and supporting nurses in other areas of the hospital.

9. HFSNs can extend knowledge in primary care of how to manage heart failure patients and carers. They can provide education and advice about heart failure, its treatment, and what to do after hospital discharge. They can help identify patients who need further care and coordinate care with other members of the MDT.

10. There needs to be a pathway in place to enable patients to have an accurate and definitive diagnosis of heart failure and to start the correct treatment in the community. In some areas, patients discharged from HFSNs, or assist in the palliation of patients with advanced heart failure. HFSNs can extend knowledge in primary care of how to manage heart failure patients and carers. They can provide education and advice about heart failure, its treatment, and what to do after hospital discharge. They can help identify patients who need further care and coordinate care with other members of the MDT.
Heart failure – the inability of the heart to perform its pumping function adequately – causes distressing symptoms and, at its most severe, has a worse outcome than many common cancers. Because of the increasing age of the population, and greater numbers surviving heart attacks, heart failure is becoming an ever increasing burden on our health services.

A number of clinical trials have shown that heart failure specialist nurses (HFSNs) can improve the management of patients with heart failure. Following the successful pilot of funding 16 HFSNs in 2001, the British Heart Foundation (BHF) approached the Big Lottery Fund (BIG) for additional funding. Consequently, 76 HFSNs were employed by primary care trusts (PCTs) in England, who were funded by BIG and managed and supported by the BHF. However, unlike the clinical trials where heart failure specialist nurses were usually associated with, and supervised by specialist centres, our heart failure nurses have been working in the ‘real world’ in disparate areas of England.

This report records an independent evaluation of the work of these nurses which was undertaken by researchers at the University of York. It confirms that heart failure specialist nurses provide great benefit and much comfort for patients with heart failure, and their carers. Importantly, for our cost conscious health-care environment, it also confirms that these nurses save the NHS money by managing patients’ problems at home and preventing or delaying costly and distressing hospital admissions. Most importantly, the report also points to significant lessons that should inform the organisation of future heart failure services.

This report typifies the British Heart Foundation’s approach to heart health. We have pioneered a new service, demonstrated its effectiveness with the support of Big Lottery Fund, and identified important issues that need to be considered in establishing effective services. It is now up to the health services to use this information to rise to the challenge of delivering appropriate care to all heart failure patients in the UK.

Peter Weissberg
Medical Director – British Heart Foundation
## Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Executive Summary</td>
<td>6-9</td>
</tr>
<tr>
<td>Chapter 1.</td>
<td>Introduction: Introduction: Background, aims, methods, measures, timeline</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.1 Background</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>1.2 Aims of the evaluation</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>1.3 Evaluation Framework: methods, measures and timeline</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>1.4 Method of presenting data, analyses and findings</td>
<td>15</td>
</tr>
<tr>
<td>Chapter 2.</td>
<td>Patient and carer access to community-based specialist heart failure care and management: Exploring the perceptions of heart failure specialist nurses and multidisciplinary team professionals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.1 Aims</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>2.2 Findings</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>2.2.1 Delivery of heart failure specialist nurse services</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>2.2.2 Extending knowledge</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>2.2.3 Equality of access to specialist care</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>2.2.4 Negotiating multidisciplinary boundaries</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>2.2.5 Impact of changes within Primary Care Trusts and moving ahead</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>2.3 Interviews with the multidisciplinary team</td>
<td>36</td>
</tr>
<tr>
<td>Chapter 3.</td>
<td>Interviews with South Asian patients and carers</td>
<td>46-53</td>
</tr>
<tr>
<td>Chapter 4.</td>
<td>Service impact on Health Related Quality of Life and satisfaction with care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4.1 Recruitment for Quality of Life and satisfaction with care survey</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>4.2 Health related Quality of Life and satisfaction with care: Patient survey</td>
<td>56</td>
</tr>
<tr>
<td></td>
<td>4.3 Health related Quality of Life and satisfaction with care: Carer survey</td>
<td>66</td>
</tr>
<tr>
<td>Chapter 5.</td>
<td>Service impact on hospital admissions and cost benefits</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5.1 Hospital Episode Statistics and Audit data</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>5.2 Economic Analysis</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>5.3 Results</td>
<td>71</td>
</tr>
<tr>
<td>Chapter 6.</td>
<td>The eight questions: key points and conclusions</td>
<td>75-81</td>
</tr>
<tr>
<td>Chapter 7.</td>
<td>Discussion</td>
<td>82-89</td>
</tr>
<tr>
<td>References</td>
<td></td>
<td>90-91</td>
</tr>
<tr>
<td>List of models and appendices</td>
<td></td>
<td>92-140</td>
</tr>
</tbody>
</table>
Acknowledgements

We would like to thank:

The Big Lottery Fund and the British Heart Foundation for commissioning this research.

All the heart failure specialist nurses for their time and commitment to all aspects of the research, especially those who participated in a series of interviews.

The health and social care professionals who participated in interviews at the end of the research process.

All the patients and carers who completed our survey on quality of life and satisfaction with care on three occasions over a year.

We are particularly grateful to the patients and family carers who agreed to be interviewed to tell us about their experiences of the heart failure service they were receiving.

The Research Advisory Group for their enthusiasm and insightful comments over three years: Dr Michael Davies, Mr and Mrs M Hodgson, Stacy Sharman, Jackie Lodge, Shai Davies, Maureen Hopkinson, Karl Atkin, Ros Brownlow, Jill Cowley, Susie May and Hayley Pryse-Hawkins.

Professor Martin Bland for advice on the development of the model used in the cost-benefit analysis.

Finally, a special thanks to Jessica Hemingway for bringing the report together.
Executive Summary

Introduction

It is known that, with appropriate support from other healthcare disciplines, heart failure specialist nurse services based in secondary care improve clinical outcomes for heart failure patients. It was less clear how best to deliver services in the community, addressing issues of access and equity, and how these services may impact on patient wellbeing and NHS costs. In 2004, following a successful British Heart Foundation (BHF) pilot study of heart failure specialist nurses based in hospitals and/or the community, The Big Lottery Fund (BIG) funded 76 heart failure specialist nurse (HFSN) posts in 26 Primary Care Trusts (PCT) groups in England. The BHF administered the funds, and managed and supported the nurses.

Our evaluation followed the project for three years and sought to answer the following questions:

1. Did the new services improve patient access to specialist heart failure care? To find out, we examined the nurses’ caseloads and the patterns of referral to their services.

2. Did introducing the service extend the knowledge of the wider healthcare team about effective methods of managing heart failure? We interviewed 25 nurses and 40 other members of the multidisciplinary team (MDT) at seven of the research sites.

3. How should services be organised? We examined barriers and facilitators to good practice and effective service delivery.

4. Did the service meet the needs of the South Asian patients? We know this population has a high prevalence of coronary heart disease but often poor access to services. We interviewed 17 patients and 11 carers.

5. Did the service affect the patients’ health related quality of life? How satisfied were they with the service? We measured, using questionnaires, health related quality of life, self-care behaviours and satisfaction with care before the nurse intervention and at six and 12 months after the first measure.

6. How does the caring role impact on family carers, and is this role and their quality of life affected by the new service?

7. Did the service reduce all cause admissions to hospital? We compared hospital admissions data obtained from Hospital Episode Statistics (HES) before and after the introduction of the new service. We also compared admission data entered by the nurses into the Athena database over a one year period April 05-March 06 with HES admissions data for the same period.

8. What was the impact of the service on healthcare costs? We assessed the overall costs of providing the heart failure specialist nurse service and then compared this with the potential cost savings the heart failure nurse service brings to the NHS in admission costs.
Methods
As this project was a complex intervention involving a variety of health and social care personnel collecting different types of data, we used a mixed methods approach to the evaluation. We used qualitative methods through case studies and interviews to answer questions 1-4. We used quantitative methods through audit, survey and cost-benefit analysis to answer questions 5, 6, 7 and 8.

Findings
The nurses achieved and often exceeded the benefits that we had anticipated.

1. Access to appropriate support and treatment. The 76 nurses saw approximately 5,000 new patients a year, the great majority of whom had at least one home visit. The nurses maintained an active caseload of around 60 patients with a much larger pool of discharged ‘stable cases’ who could be brought back into the caseload if required. In general, nurses saw approximately 34% of all people coded with heart failure on hospital discharge in the PCT in which they were based; many of these patients would formerly have received no ongoing specialist care. Basing the nurses in primary care made it easier to deliver care to older and more infirm patients. However, there is a tension between improving numbers of people able to access the service through community-based clinics and maintaining the quality of a patient-centred service with home visits. The nurses improved quality of care in numerous ways: by providing continuity of care, a feature greatly valued by patients; by titrating and changing medications and by some nurses being able to prescribe, which is especially valuable in an acute exacerbation of the illness; by building links to routine primary care monitoring systems and by gaining access for patients to other services such as rehabilitation and palliative care.

2. Dissemination of good practice through the team was evident from interviews with medical colleagues and the changes made to patient pathways where HFSNs educated and involved different professionals from primary, secondary and community care services. There was evidence of better communication practices between General Practitioners (GPs) and cardiologists, since HFSNs worked as key mediators. Good communication between HFSNs and practice nurses, district nurses and community matrons is important for good patient care. HFSNs disseminated knowledge of how best to manage the ‘stabilised’ patients to primary care staff and encouraged a more holistic model of care encompassing not just medical but also psychological, social, rehabilitative and palliative care. Many of the nurses initiated innovative service improvements, examples include: day therapy in a hospice, support groups, one stop heart failure clinics, cardiac rehabilitation programmes, intravenous therapy in the community, early discharge support, and using heart failure health care/support assistants for collecting bloods and checking on patients.

3. There were some commonly experienced problems for the nurses in establishing and developing their services. Trust was often hard won from GPs and Consultant Cardiologists, local barriers to nurse prescribing reduced the potential benefits of the nurses, there was sometimes confusion about the appropriate supervision of a specialist nurse working in primary care, and building a network of referrers or establishing local pathways and protocols often took a considerable amount of effort that reduced patient contact time. The most important facilitators for nurses were: active and well attended MDT steering groups, ongoing training and support provided by the BHF, when local doctors and consultants
acted as champions of the service, where clear local pathways were developed and adhered to by all practitioners, when the nurses’ skills were recognised and they were able to work largely autonomously in particular to alter existing drug regimes and to prescribe.

4. On the whole, the needs and experiences related to heart failure, and the benefits of the HFSN service, are similar for minority ethnic patients and white patients. It is possible to provide an equitable service to people of ethnic minority backgrounds without pre-defining their needs as special or different in terms of culture, religion or linguistic background, and services in some areas achieved this goal. However, it appears that even where the resources are available, stereotypical assumptions about cultures of ethnic minority groups, and a focus on difference to the exclusion of similarities in needs and experiences, can result in barriers to referrals and access to services for patients and carers from minority ethnic groups.

5. Health related quality of life was significantly improved by seeing a nurse and with care was high. Interestingly, the nurses were seeing patients whose quality of life measured by the Minnesota Living with Heart Failure (MLHF) questionnaire was significantly lower than those seen in many research studies of heart failure management programmes or drug trials. There was a significant improvement in the quality of life score at 6 and 12 months compared to the score at first contact with a nurse, as measured by the MLHF and by a generic quality of life measure the Short Form 12 (SF12). Patients reported good self-care behaviours on first completion of a self-care questionnaire (European heart failure self-care behaviours scale) and this decreased slightly at 6 months and 12 months. Anxiety and depression scores did not improve when measured by the Hospital Anxiety and Depression Scale (HADS) but changes were not clinically significant. Patients were highly appreciative of the service.

6. Carers’ physical health, measured by the SF12, though better than that of the patient, was lower than the general population and got slightly worse over the 12 month follow up. Their mental wellbeing was similar to that of the patient and improved over time. We used a care-giving demands scale to measure the physical and supervisory demands of caring, the impact caring had upon their social and emotional wellbeing and upon finances. All scores improved slightly during the year. Carers also reported being very satisfied with the service.

7. Comparisons with historic data revealed a 35% reduction in admissions. Nurses, GPs and cardiologists interviewed report this as being most likely due to: improved monitoring of renal function and fluid status; appropriate medication changes and through working closely with other members of the MDT. When admissions did occur they were more likely to be necessary or planned and therefore patients with a heart failure specialist nurse stayed in hospital slightly longer than when compared with before the nurses were in post. Despite this, admissions lasted on average no longer than the national average for an admission for heart failure.

8. Cost benefits were evident mainly through a reduction in unplanned admissions. We estimated a saving of around £1,826 per patient seen after the costs of the nurse are subtracted. This amounted to an overall saving for the NHS of £8,050,834 per year.
Conclusions

The evaluation demonstrated that the introduction of heart failure specialist nurses based in primary care is feasible and is highly valued by patients, informal carers, GPs, cardiologists and the wider multi-disciplinary healthcare team. It is clear that basing heart failure specialist nurses in the community provides some unique advantages, however strong links with secondary care are essential to avoid missing a significant number of patients who would benefit from the service. There is a strong indication that instituting such a service may help to reduce unplanned admissions whilst significantly reducing healthcare costs. People from ethnic minority groups can benefit equally from the service, including those whose first language is not English. However, some are excluded from the service due to health professionals’ mistaken assumptions or structural barriers to referral, including lack of interpreters.

Recommendations

These services are clinically and socially valuable and have the potential to reduce healthcare costs; they should be available for all patients with heart failure. Where this is felt appropriate, patients should have the choice of attending clinics or of receiving care at home. Services would be significantly improved by better joint working between primary and secondary care. Further work is required to find ways to deliver this care to groups that are under represented such as elderly patients who are not under the care of a cardiologist and those from minority ethnic groups.
Chapter 1

Introduction: Background, aims, methods, measures, timeline

1.1 Background

Heart failure affects about 2% of the population with an annual incidence of 0.5-1%. There are approximately 63,000 new cases each year in the UK and 878,000 people who suffer from definite or probable heart failure. The prevalence is increasing due in part to improved survival following myocardial infarction and in part because it is strongly associated with age. This is increasing demand on the health service.\(^1\) The National Service framework for Coronary Heart Disease (2000) highlighted that people of South Asian origin have a higher incidence of coronary heart disease and younger age at first admission for heart failure compared to their white counterparts, and are under-represented in research into heart failure management.

Patients typically have multiple medical conditions, complex medication regimens,\(^2\) unpredictable exacerbations, disabling symptoms that include fatigue and breathlessness, limited functional status and a poor quality of life.\(^3\) Frequent rehospitalisation is common with as many as 40% of patients being re-hospitalised within six months of discharge after an acute event.\(^4\) Treatment costs take about 1.8% of the NHS budget, and heart failure accounts for around 5% of acute admissions, and 10% of bed occupancy. It is a leading cause of death in the UK; there is 40% mortality at 1 year, and 10% per year thereafter.\(^5\)

Recent years have seen policies to expand the role of nursing, one result has been the development of the role of specialist nurse.\(^6,7\) There has also been an improved balance between generalists and specialists to provide integrated networks of specialist and continuing care in the management and support of patients with long term conditions.\(^7\)

Evidence of effectiveness of Heart Failure Specialist Nurses

Most heart failure specialist nurse (HFSN) services concentrate on early intervention with inpatients, optimising therapy prior to discharge, followed by effective discharge planning and providing continuity of care after discharge.

There have been several studies of the effectiveness of such nurse-led care. Those using multidisciplinary, nurse-led home or clinic based interventions\(^8,10\) have shown positive effects on readmissions. A reduction in adverse clinical outcomes and healthcare costs for patients with heart failure has been reported as a result of patient education and support.\(^4\)

Description of the service to be evaluated

As part of a coordinated approach to patient care, the Department of Health\(^11\) has endorsed the use of specialist nurse-led heart failure services in primary and secondary care. Initially this tended to be a hospital-based service, with little provision for outpatient, community, and home based services. This was not ideal since cardiovascular disease, and specifically heart failure, is chronic and well suited to management in the community and many patients are very ill, elderly and housebound. In recognition of this, nurses with years of
cardiology and general medical experience have been employed to work in the community more recently.

The Heart Failure Specialist Nurse Service for England is a collaborative project between two organisations. The British Heart Foundation (BHF) is a national charity funding research into the causes, diagnosis, prevention and treatment of heart disease, as well as funding specialist nurses. The Big Lottery Fund (BIG) is responsible for giving out half the money for good causes raised by the National Lottery. BIG is committed to bringing real improvements to communities and the lives of people most in need.

In recognition of the ever increasing numbers of people in England living with heart failure, and the need to provide services nearer to where they live, the Big Lottery Fund, working with their award partner The British Heart Foundation invited applications from Primary Care Trusts (PCT) for funding to employ heart failure specialist nurses based in the community in England for three years. In 2004, seventy six nurses were allocated to 63 PCTs in 26 PCT groupings.

We, the BHF Care & Education Research Group at the University of York, were invited to evaluate the development and impact of these services.

1.2 Aims of the evaluation

The evaluation aimed to:

1. Assess whether the service improves patient access to specialist heart failure care, particularly within the community.
2. Explore whether the service extends knowledge on effective methods of managing heart failure amongst the multidisciplinary teams.
3. Examine those things that act as barriers to establishing a service and those things that facilitate good working practices.
4. Examine how people of South Asian origin experience their heart failure care.
5. Measure the effect of the service on patients’ quality of life and satisfaction with specialist heart failure care.
6. Examine the impact of the caring role on family carers, and whether the service affects this role and their health related quality of life.
7. Determine whether the service reduces all cause admissions of heart failure patients.
8. Examine the costs and potential for cost savings through introducing the service.
### Evaluation Framework: methods, measures and timeline

#### Evaluation Framework

The evaluation incorporated both quantitative and qualitative methods. Using a comprehensive evaluation framework offered the opportunity to learn from the implementation process and the influence of the PCT context on programme effectiveness, rather than concentrating solely on outcomes. Each of the eight questions was answered using one or more of the methods and data sources described below.

#### Methods

##### Quantitative methods

Quantitative methods included audit, questionnaires and collecting data from government sources.

**Audit**

Nurses in each centre were provided with a patient management database, Athena. They used it to record: patient demographic and clinical information including medications, co-morbidities, and admissions to hospital; nursing process data such as the number of contacts by the nurse, referrals to other health and social care staff. Nurses also collected information on readmissions: the number, the reason and the duration. The full list of variables collected by Athena is shown in Appendix 4. The data required for the evaluation were anonymised and sent to York University for analysis.

Nurses also completed quarterly monitoring reports for the BHF recording number of face-to-face contacts, telephone contacts, and the number of teaching sessions they had completed for other healthcare workers. These were collated and summaries sent to the University of York.

##### Questionnaires

Nurses were asked to give a study information pack to all patients and their carers who met the following inclusion criteria.

**Inclusion criteria:**

- All patients diagnosed with heart failure and their main carer who are referred to the HFSN
- Living in the community
- Willing to accept the HFSN service
- Do not meet any of the exclusion criteria.

**Exclusion criteria:**

- Written case record of cognitive deficits
- Unable to make daily decisions about their own care
- In residential care.

**If an individual decided to participate they filled in the following questionnaires:**

- a generic HRQOL measure, the SF12
- a disease specific HRQOL measure: the MLHF
- a measure of anxiety and depression: the HADS
- the European Heart Failure Self-Care Behaviour Scale.

**Carers were asked to complete:**

- the SF12
- the Care giving Demands Scale. This measured the physical impact of caring and how it can alter roles and finances.

These measures were completed again at 6 month and 12 month follow-up. At the six month and 12 month follow-up they also completed a Satisfaction with care measure.

All of these measures have been found to be valid and reliable, and most have been used in this population previously.
All data was entered into a statistical analysis package, SPSS and analysed by an experienced statistician using a variety of parametric and non-parametric tests.

Use of health services

Data on the number of admissions to hospital for heart failure in the year preceding the study were requested from each PCT. Hospital Episode Statistics (HES) data were also obtained to enable comparison between the years before a heart failure service was in place with the years since the nurses had come into post.

Economic data

We considered the relative costs of providing heart failure specialist nurses and established whether these costs benefit the overall use of National Health Service (NHS) resources. We assessed the overall costs of providing the heart failure specialist nurse service and then compared this with the potential cost savings the heart failure nurse service brings to the National Health Service (NHS) in admission costs.

Qualitative methods

Interviews

Interviews were conducted in a sub set of seven of the 26 centres. The HFSNs and other members of the healthcare team were interviewed; the nurses at three time points and other healthcare staff towards the end of the three year funding.

The HSFNs were asked about: service delivery, referral patterns and caseloads, working with the MDT. Members of the multidisciplinary team were asked to describe how they were working with the HFSNs, and how they perceived the contribution of these nurses in providing care and access to other services for patients and their carers.

Interviews with patients and carers from ethnic minority groups

To examine the experience of patients of South Asian origin in accessing the HFSNs, interviews took place with patients and carers who had accessed the service, to gain their views of the service and any changes in their health related quality of life.

Interviews were conducted by two different researchers who used different theoretical frameworks appropriate to the topics under consideration for the analysis.

Ethical considerations

The study was approved by a Multi-centre Research Ethics Committee (MREC) and Research Governance and Management departments of participating centres. Written informed consent was gained from all participants and they were reassured of confidentiality and anonymity.

Timelines

Nurses came into post between April 2004 and 2006. Once the nurses had received their training and orientation and started to receive patients into their caseload they began to recruit patients into the questionnaire study. Due to the late start of some nurses, recruitment of patients continued until September 06.

The Audit began in April 2004 and the audit database was provided to the sites over a period of 18 months. There were many difficulties in some areas with getting the database installed, data entered and being able to transfer data to York. By August 07 all but three PCTs had managed to transfer data to York, yielding approximately 18 months of data.

HFSNs working in each of the seven sampled sites were approached to participate in the qualitative study (March to June 2005). They were informed about the aims of the qualitative study, the sampling procedure and the time
implications associated with the study (for interviews and completion of reflective diaries). Information sheets about the study were provided and informed consent obtained from all HFSNs (n=23). At interim interview point (January to March 2006), two further HFSNs were employed in the sampled PCTs. Consent was obtained from them; one of these nurses has since left their post at time of reporting. Two interviews (initial and interim) have been carried out with 23 HFSNs and initial interviews with 2 HFSNs.

Interviews with the multidisciplinary team, South Asian patients and carers and exit interviews with 20 of the 25 nurses took place between November 2006 and July 2007.

**Methods for addressing each of the 8 evaluations questions**

1. Did the new services improve patient access to specialist heart failure care? To find out we examined the nurses’ caseloads and the pattern of referral to their service. We did this by combining the data listed below:
   - Numbers of patient records in the Athena database
   - Numbers of new patients reported in nurse quarterly monitoring reports
   - Data from interviews with nurses and the multi-disciplinary team in seven sites

2. Did introducing the service extend the knowledge of the wider healthcare team about effective methods of managing heart failure?
   - We interviewed nurses and other members of the multidisciplinary team at seven of the research sites.
   - We looked at the number of teaching sessions reported in nurse quarterly monitoring reports

3. How should services be organised? We examined barriers and facilitators to good practice and effective service delivery by analysing data from interviews with nurses and other healthcare staff.

4. Did the service meet the needs of South Asian patients? Questionnaires may not be feasible or appropriate for this group to find out about quality of life, access to and satisfaction with services. So we invited a sample of patients from nurse caseloads on the Athena database to be interviewed, and asked patients and carers about their experiences of their heart failure care.

5. Did the service affect the patients’ health related quality of life? How satisfied were they with the service? We measured, using questionnaires, health related quality of life, self-care behaviours and satisfaction with care before the nurse intervention and at six and 12 months after the first measure.

6. How does the caring role impact on family carers, and is this role and their quality of life affected by the new service? They completed the care giving demands scale and SF12 questionnaire when first meeting the nurse, and again after six months and 12 months. They completed the satisfaction with care at six months and 12 months after first meeting the nurse.

7. Did the service reduce all cause admissions to hospital? We compared hospital admissions data obtained from Hospital Episode Statistics (HES) before and after the introduction of the new service. We also compared admission data entered by the nurses into the Athena database over a one year period April 05-March 06 with HES admissions data for the same period.

8. What was the impact of the service on healthcare costs? We assessed the overall costs of providing the heart failure specialist nurse service and then compared this with the potential cost savings the heart failure nurse service brings to the NHS in admission costs.
Using mixed methods adds depth to an evaluation such as this, but presents some logistical problems in the presentation because methods of analysis and reporting findings are so varied. In the following chapters we will present the results of the qualitative and quantitative investigations separately, then synthesise the results using each of the 8 questions highlighted above.

Chapter 2 will present data mainly from the qualitative sub study, but including where appropriate, data from the audit study or other quantitative data. It will concentrate on the impact the nurses had on access to care, models of service delivery and ways of extending knowledge of how to manage patients with heart failure. The chapter takes the perspective of the nurses and other key members of the healthcare team.

Chapter 3 will present data from the interview study of the value of the service to people of South Asian origin.

Chapter 4 will present the methods and the results of the questionnaire survey.

Chapter 5 will present the quantitative data on hospital admissions and the economic impact of the nurse service using data taken from PCTs, HES and NHS costs data sources.

Chapter 6 will present each question in turn, synthesising data from both the qualitative and the quantitative evidence as a set of key findings.

Chapter 7 will discuss the findings.
Chapter 2

Patient and carer access to community-based specialist heart failure care and management: Exploring the perceptions of heart failure specialist nurses and multidisciplinary team professionals

2.1 Aim

The aims of the qualitative sub-study in seven case study sites were to explore and compare heart failure specialist nurses’ (HFSNs) and multidisciplinary team perspectives and experiences on:

1. How (and whether) the development of heart failure specialist nurse services were enabling patients and their carers to access community-based specialist heart failure care and management.

2. How (and whether) the service is extending knowledge on effective methods of managing heart failure amongst the multidisciplinary team.

Methods

A longitudinal interview study was carried out. The study uses the theoretical framework of access developed by Aday et al. Model 2 in the appendices provides an overview of the access framework. Essentially, health policy has a role in influencing the characteristics of the health delivery system and the population served by it. This theoretical framework provides parameters for the study, guides data collection and provides an anchor for interpreting data.

Participants

Seven PCTs were sampled to represent a range of services based on the following: number of BHF HFSNs; number of existing nurses providing heart failure services (primary/secondary care); number of PCTs covered by the services; number of hospitals covered by the service; geography (rural, urban, inner city); heart failure prevalence rates; PCT population (for example high numbers of minority ethnic groups or elderly). Appendix 6 provides details of the sampled PCTs and a summary of HFSNs employed in the PCT (including qualifications and clinical experience).

Data collection

First interviews were carried out either with an individual nurse or as a group representing the service. This was decided by the HFSNs in each sampled site (Appendix 7). Reasons provided for choice of interview style were varied and include: an opportunity for individual nurses to provide their perspective; variation in terms of being ‘established’ in the role; anticipated difficulties of having ‘shared’ views; presenting a shared view; an opportunity to meet with nurse colleagues and learn about developments in neighbouring PCTs. Interim interviews were carried out with individual HFSNs by telephone.

Exit interviews with HFSNs were conducted to understand any changes in the working pattern and conditions of the BHF nurses since the interim interview, how they perceived the future of the service within the context of macro level changes within PCTs, and associated uncertainty regarding their role once the BHF funding came to an end.
Towards the end of the study, interviews with a purposive sample of professionals representing a range of disciplines working within a multidisciplinary team/framework alongside HFSNs were carried out to understand their role in supporting the nurses, and how they perceived the contribution of the nurses in providing better care and access to other services for patients and their carers. Whilst we tried to make the sample comparable by selecting key professionals at each site, including at least one lead cardiologist, a GP and/or care of the elderly physician, and a palliative care consultant or nurse, the diversity between sites meant that we had to achieve a balance between the specificity of the site and representativeness of the sample.

**Data analysis and rigour**

All interviews were recorded (with the participant’s consent), and transcribed verbatim. For analysis of data from first and interim interviews, a qualitative data analysis management software package (QSR Nvivo v.2) was used. Data were analysed for thematic content and comparisons made within (that is between HFSNs in a PCT) and across the case studies (or PCTs). Constant comparative methods were used to analyse data from exit interviews and with the multidisciplinary team. Analysis of findings from the data-set related to exit interviews has been informed by the local picture provided by the MDT interviews at each site. Analysis looked at similarities and differences within and across sites, within the context of analysis of the data from professional interviews as well as the local history of service and background of the nurses. Analysis unpicked the main themes explored in the topic guide, linking differences and similarities in perceptions across disciplines within and across sites. This approach provides a useful way of analysing the strong and weak links within and across sites and focusing on the specificities of the case study site in terms of multi-disciplinary links and local initiatives within the context of broader changes happening at a macro level.

**Ethical considerations**

The study was approved by a Multi-centre Research Ethics Committee (MREC) and Research Governance and Management departments of participating centres. Written informed consent was gained from all participants and they were reassured of confidentiality and anonymity.

**2.2 Findings**

Two interviews (initial and interim) were carried out with 23 HFSNs and initial interviews with two HFSNs. Exit interviews were conducted with 20 out of the 25 BHF nurses who had taken part in the study at the beginning (see Appendix 9 for details), five of whom had since left the service. Twelve nurses opted for individual and eight for joint interviews. Whilst some of these vacant posts had been filled, for methodological reasons, we did not interview nurses who had not been interviewed on the previous two occasions. Forty interviews were carried out with a range of professionals including PCT line managers and BHF co-ordinators across primary and secondary care services at each case study site (see Appendices 8 and 14).

**Context**

At inception, the HFSNs were establishing services to ‘fit’ within existing organisational structures. This meant that the starting point for service delivery and developments varied across the case sites. HFSNs in one case site (11) were establishing completely new services. The majority of HFSNs were developing community-based services to integrate with established secondary care heart failure services (n=4; case sites 2, 15, 17 and 26). Two case sites were integrating into developing structures for the delivery of heart failure services across the secondary-primary care interface (case site 22 and 25). Appendix 6 provides contextual detail and characteristics of the case sites. These contexts were important to HFSNs’ perceptions of their ability to develop their community-
based services to improve access to specialist services for heart failure patients and their carers. In some areas, the HFSNs perceived that they had a ‘blank canvas’ (26: HFSN 4; Int 1), while in other areas they were ‘hitting the road running’ (22: HFSN 17; Int 1).

In areas where the HFSNs were developing existing services it was suggested that there was generally a more positive acceptance of the service by the multi-disciplinary team. This was attributed to familiarity with the purposes of the HFSN service by the MDT and an ability to generate referrals to the service. In areas where heart failure services were less developed, or in one case non-existent, the HFSNs had to spend intensive amounts of time informing MDTs about the service and its aims and generating referrals.

2.2.1 Delivery of heart failure specialist nurse services

When considering the delivery of HFSN services it is important to recognise the ‘availability’ of the service and the ways in which the service is organised. These factors are crucial for understanding how the service is accessed and utilised by heart failure patients. All HFSNs were providing home visiting; in some areas this was the only way in which care was being delivered whilst other HFSNs were home visiting and establishing heart failure clinics. The organisation of the service through home visiting and clinics influences the types of patients being consulted by HFSNs. However, this also influences the numbers of patients that HFSNs are able to ‘actively’ manage on their caseloads. Each of these issues is explored further below.

Home Visits

HFSNs highlighted that home visits enable the service to reach patients who may otherwise not receive the care they need for treatment and management of their condition. For example, patients with advanced heart failure and complex problems and co-morbidities, frail and elderly patients who find it difficult to get to hospital clinic appointments, and those who are socially isolated, particularly in rural areas:

…the socially isolated patients [benefit]. Particularly in my area which is very rural and a lot of people can be living on their own and live in a little village and never see anybody from day to day… the fact that I’m going to see them to check on a swollen ankle or to increase their medication on a fairly regular basis really improves their quality of life… And I can’t quite put my finger on what it is other than social interaction with somebody… It is really supporting [one patient] in his own home and he said, ‘I would be in a nursing home if it wasn’t for you.’ [17: HFSN 24; Int 1]

The HFSNs report that they are an important part of service delivery for these patients because otherwise they suspect that these patients would be admitted to hospital due to gaps in service provision in primary care:

I seem to be getting the patients passed to me that are definitely struggling to get to clinics, definitely struggling to manage their heart failure, definitely the neglected population… I sometimes think if I wasn’t there, where would they go to? I think deep down I know the answer would be, they would go to their GPs and the GP would admit them. So I suppose I am making a difference. [26: HFSN 6; Int 1]

HFSNs from all case sites reported that home visiting was a time consuming component of their activity, partly because of the distances that the HFSNs travel to home visit but also because of the length of the consultation per visit:

I try to see my new patients for about an hour… and then my follow-ups I try to keep for half
I don’t achieve the quantity of numbers [of patients] I would like to see because of the driving time in between… I perhaps see about on average approximately 5 patients a day and that’s my maximum; and some days it’s 3. [11: HFSN 48; Int1]

However, HFSNs were keen to emphasise the importance of the home visiting service for the successful care and management of heart failure patients. The home visit was viewed as essential for establishing patient and carer understandings of the heart failure diagnosis immediately after discharge. Some HFSNs suggested that patients do not always understand their diagnosis and so the visit allows the HFSN to explain the condition and its management:

Definitely some [patients] are really hearing heart failure for the first time, are taking notice of heart failure for the first time… It’s really difficult isn’t it to know what people have been told because it all depends what they’ve understood and how much they’ve absorbed and things, you know. We have gone to their homes and talked to people about [heart failure] more than what they’ve probably had on the ward and it just seems as though it’s the first time they’re hearing it. And I’m sure it isn’t, I’m sure some of it is how you absorb information in hospital or how it’s told. [26: HFSN 3; Int1]

Other HFSNs indicated that following diagnosis, patients and carers do not understand that the condition can be actively managed and thus home visits enable the HFSN to spend time with patients and carers to support them following diagnosis and to educate them to improve their longer term self-management of the condition:

When they’ve been told that they’ve got heart failure, they just think, well that’s the end; they just almost go home desperate. And then suddenly [a HFSN] comes along and we’re looking at treatment and everything. We don’t give them false hope obviously, but it’s just giving them the support… you’ve taken the time to explain things and that’s what they’re really appreciative about. Just having somebody go through things in simple terms explaining what’s happened and how you’re going to treat it and then of course it pays off because they’re more compliant with the medication because they understand why they’re taking it and how it’s working. [15: HFSN 59; Int2]

**Clinics**

The development of clinics in the community is also an important way in which HFSN services manage their caseloads. In two case sites, the HFSNs were immediately able to integrate into clinic-based services that were developing prior to their appointment. In the case sites where the HFSNs were integrating with existing secondary services, the majority (3/4) were initiating community-based clinics by second interview. HFSN services in one of the case sites were struggling to determine how their clinics could be set up and integrated within well established secondary care services, even though the HFSNs recognised a need for strategies to better manage their caseloads (case site 17). However, in the case site where there had been no existing services, the HFSNs were exploring and piloting the usefulness of community-based clinics with one HFSN.

For HFSNs in case sites where clinics were well established in the secondary care setting, the HFSNs used these clinics to manage patients who were able to get to the hospital for appointments. In addition, as the service has developed, the HFSNs have also started to run community-based clinics to widen access to specialist services for patients:

(Name PCT), we run the clinic there and see patients out there which a lot of it is quite rural… and you see patients from different backgrounds, like farming communities. The [name PCT] clinics tend to be quite small clinics but quite easily accessible for those patients out there because it’s quite a way a
Within case sites, there was variability across the PCTs in establishing HFSN clinics. This created big differences in the numbers of patients that HFSNs were able to have on their caseload and therefore the availability of the service. In case site 26, clinics had enabled two HFSNs to manage about 100 patients each, but where clinics had not been established caseloads remained at about 30 for each HFSN.

HFSNs located in one area indicated that they could see the benefits of trying to establish clinics, in terms of their productivity and being able to consult with more patients. However, they could not determine how best to go about setting up such clinics. In another area, HFSNs were piloting whether linking a nurse clinic with a GP with a special interest (GPwSI) in heart failure would improve access for patients and prove to be a more efficient use of the HFSNs’ time. In principle, HFSN clinics appear to be an efficient way for the HFSNs to provide care to more heart failure patients, therefore improving access. However, in case site 22 (where the services are more established) concerns were expressed about the care (and its quality) that HFSNs were able to provide within clinic appointments, and the extended waiting lists (due to large caseloads) that might be impacting on timely management of the condition for patients:

I think there’s an issue of time; the amount of time that you can spend with patients and relatives. We still provide the education and [drug] up-titration and monitoring and the contact if they de-compensate, you know. There is a way in for them to contact us if they’ve got an issue. But I don’t know that we always have enough time with the educational and supportive side of things that traditionally nurses do and in a way I see that the clinics are turning a little bit to being a more medical model in a way and maybe we’re in danger of, we’re almost heading into, cheap doctors. [22: HFSN 20; Int2]

I mean it’s taken off really well and the patients seem very happy apart from the clinics are getting bigger so they’re waiting longer… But especially with this clinic at the [name hospital], patients are now waiting two months for the beta-blocker slot of appointments, we’re not getting beta-blockers done as soon as possible. So I don’t know whether it’s like a victim of your own success or what, but I feel frustrated sometimes that we’re not getting the patients in quick enough. [22: HFSN 18; Int2]

The majority of HFSN services are available between the hours of 9 to 5. HFSNs commented that this created difficulties because patients requiring support and management outside of these hours were unable to contact the specialist service. In one area the HFSNs described keeping their mobile phones on to respond to urgent calls:

Patients know they can make contact with me by my mobile telephone and I tend to leave it on and perhaps inappropriately it stays on; I don’t even turn it off when I get home. I have to say on the whole, I’ve perhaps had 3 patients that have phoned me out of considered hours and have been advised appropriately about what to do. I certainly wouldn’t be driving in the middle of the night to see a patient, that would be totally inappropriate. I would be advising them to go through the appropriate channels. But sometimes just to hear a voice from somebody that you know quite well and for you to be able to say to them, you need to get the GP out… I think it just reassures the patient. [11: HFSN 48; Int1]

In one case site (22), the HFSNs had set up an out of hours on call service. This was in response to problems arising with the timing of results coming back from the lab (after 5pm) and then no response being taken until the morning because a HFSN was unavailable after this time. The HFSNs indicate that this has...
improved communication and ensures that care is delivered in a timely and appropriate manner to patients. It also means that there is a HFSN available when required by patients:

When I’ve been on call, I have had patients ring me and they say, well I’ve not been very well all week really but I didn’t like to do anything and now I know the doctors is shut and, you know, it’s 5 o’clock. And you say, just take an extra [medication] at lunchtime over the weekend and I’ll be in touch Monday. You end up having to put them on additional medications on Monday but you think, well perhaps maybe we have kept them out over the weekend because I’m sure if an on-call doctor had seen them, they would have admitted them. [22: HFSN 18; Int2]

In addition to home visiting and clinics, HFSNs in some areas are exploring additional avenues for the provision of specialist care and management to heart failure patients. A variety of initiatives are being explored by HFSNs to increase service provision and accessibility, and to support better use of the HFSN resource. These include strategies to improve ongoing social and psychological support for patients and their carers through day care with the palliative care team (case site 22), and heart failure support groups for patients and their carers (case site 26). Clinical interventions targeted at newly diagnosed patients, such as one-stop heart failure clinic (case site 11) and patients in different stages of their illness who may benefit from cardiac rehabilitation clinics in the community (case sites 2 and 26) and heart failure exercise classes (case site 15). Other initiatives are specifically aimed at decreasing the amount of time that patients are in hospital, such as intra-venous therapy management at home (case site 26) and early discharge support of heart failure patients (case site 2). In one case site, the HFSN service is employing healthcare assistants (HCAs) to support and improve efficient use of the specialist nurses’ time:

It’s more from a stand view point of managing the caseload efficiently, effectively and using our resources wisely. That’s the issue I think more than anything. [22: HFSN 19; Int1]

Activities carried out by HCAs include preparing for clinics, administrative roles (such as obtaining test results and responding to patient calls), telephone reviews of stable and newly referred patients, and some home visits to stable patients. Both HCAs were experienced, with a recognised qualification (diploma or NVQ) and cardiology experience. They are described by HFSNs as a ‘valuable asset’ [22: HFSN 17; Int2]. Over time, the HFSN services have to organise their services and establish ways of working to maximise best use of any specialist time with heart failure patients.

Realised access: Referrals and caseloads

This section explores the demand for, and utilisation of, HFSN services and the HFSNs perceptions of how satisfied patients, carers and other health care professionals are with their service. Utilisation of the HFSN service can be recognised through the numbers of referrals and the HFSNs strategies for managing increasing demands for the service.

Source of Referrals

tAll HFSNs were receiving referrals from secondary care. However, the ways in which this was being achieved varied across the different case sites. In 6/7 case sites, the HFSN services were supported by secondary care cardiologists. This support was perceived as important for the successful integration of the HFSN service into existing service provision for heart failure patients. In one case site, the HFSNs experienced difficulties (at first interview) for generating referrals to their service. This was due to the hostility of a cardiologist who did not support the HFSN service and would not make referrals:

The cardiologist at [name hospital] isn’t prepared to support the service although he actually signed up to it… [We are] struggling with access to patients, which to me isn’t right that public funds have been wasted on
someone, you know, who isn’t allowed to fulfil their potential. [15: HFSN 66; Int1]

This meant that the HFSN service started to look for referrals from other areas (such as medical consultants and GPs) whilst continuing negotiations with the cardiologist. By second interview, the problems were resolved and referrals had started to come from the cardiologist. HFSNs were keen to emphasise the importance of the secondary care referrals to the HFSN service because they felt that their input was most valuable with patients post acute event:

We do have a big problem in that the best kind of heart failure service, from my (point of) view, is the one that picks up someone in proximity to an acute event… If I go to a GP surgery, find someone who’s had heart failure for 2 years and is very comfortable at the moment and then say that I’m going to tinker with your tablets then they’re a lot more likely to say, bugger off basically… If you get someone in that proximity they’re more likely to make changes and take notice of what you’re saying to them. [15: HFSN 66; Int1]

In some areas the HFSNs were spending time visiting acute care wards to generate referrals to the service because they did not receive enough via the cardiologists (case sites 11 and 26):

I’m going in to look for patients on the wards, purely first because I’m in [name town] and I’m round about, so it’s a lot easier for me to do that. Secondly my background is medical admissions and I know all the girls on there so I know how it works and it’s probably easy for me to just go in and search through all their notes because they’re so busy and you don’t get a lot of input or assistance from them. So you have to do it yourself really. Because I know the place, I’ve worked there for so many years, that’s probably why I do it. [11: HFSN 50; Int1]

However, over time, and as caseloads are increasing, the HFSNs recognised that spending time trying to generate referrals this way was no longer feasible.

By second interview, HFSN services in some areas were struggling to promote their services within primary care and felt they were not receiving referrals from GPs. Some HFSNs perceived that this was because they requested a confirmed diagnosis of LVSD prior to accepting a referral, and cardiologists, rather than GPs, were involved in the diagnosis. Other reasons included a lack of understanding about the service amongst GPs, despite HFSNs efforts to promote (or launch) their service or the inability of GPs to change their referral behaviour:

Some of the GPs that I’ve spoken to have said that they would prefer not to refer directly to us but they’d like to go through the ‘traditional’ route because that’s the manner and custom that they’re used to dealing with. [25: HFSN 52; Int2]

By following the HFSNs over time, it was possible to track the development of their caseloads and sources of referrals. As well as having referrals from cardiologists and GPs, the HFSN services widened their sources of referral so that they received referrals from consultants of general medicine and elderly care. In addition, referrals came via nursing staff in secondary care wards and also clinics (cardiology nurses) and the community (such as community matrons and district nurses), occupational therapists, palliative care teams and Macmillan nurses, CHD teams, cardiac rehabilitations teams, nursing and residential homes. In addition, the HFSNs explored additional avenues, such as promoting their involvement with patients to GPs in letters reporting a positive echocardiogram result:

[We] were getting referrals from the open access echo for heart failure but we were prompting the GPs with a letter. So we would get a copy of the echo from the service and then we would write to the GPs, and we are still doing that, but that’s about to change. We’re
hoping now that we can be incorporated in the actual form that the GPs fill in for an open access echo service. So it will say on there that if the patient is referred for echo then they will automatically be referred to the heart failure service if they’re found to have LVSD… So I think that will be better. Once they know they’ve got confirmed LVSD - well I say that, there is still going to be a little tick box, the GP does have the option to opt out but if he doesn’t tick the box on the form then they will automatically be referred to us.

[11: HFSN 49; Int2]

One other way suggested by HFSNs of widening the referral base included picking up possible heart failure patients being admitted to medical admission units by GPs:

One of the things we want to do is look at, well the way the admissions work… The GPs phone bed bureau - they’ve got two emergency nurse practitioner type roles - they ring in and say they want to admit someone and they then discuss the patient with these nurses. What we were hoping to do was pilot a service where the patients short of breath and who sound like heart failure get referred to us. So we see them that day, either at home or in a clinic setting and then liaise with Dr [name] who’s a cardiologist and bring up a management plan dependent on what the patient is like.

[22: HFSN 17; Int1]

The majority of case sites had caseloads of about 25 patients when first interviewed but by second interview this was in excess of 80 patients providing both home visits and clinic based care. These increases reflect the growing demand and use of the service in some areas. In areas where the HFSNs were home visiting these numbers tended to remain smaller. However, the HFSNs were using strategies to ‘control’ their caseloads rather than this, indicating there was less demand (discussed below).

The HFSNs developed referral criteria for their service. The criteria included a confirmed diagnosis of LVSD but also required clear indication of the purpose for a referral - that is, what their involvement would provide for patients. However, not all patients referred had a confirmed diagnosis:

But then some of the [GPs] will send you such naff referrals. And you think, come on get a grip this isn’t what it’s all about… It’s meant to be secondary care referrals mainly, or ones that have slipped through secondary care referrals and the GPs pick them up and send them to us. Some of the GPs will send you anyone that’s got swollen ankles and is feeling breathless.

[17: HFSN 1; Int1]

HFSNs’ perceived that they were sometimes used as a ‘stepping stone’ service for consultants who could not make a decision about whether or not to discharge a patient and so referred them to the HFSN with no clear reason for the HFSNs’ involvement:

We’re almost a stepping stone aren’t we? And again it may not be an appropriate referral because it’s not necessarily because [the patient] is particularly unstable or because they need titration, anything specific. It’s just that the consultants haven’t quite got the confidence to say, “Right the GP can look after this patient.” “Okay we’ll let the heart failure nurse.” And then we’re left with the decision as to whether this patient should be discharged back to the GP service or not.

[22: HFSN 20; Int1]

By second interview, many of the HFSNs discussed their increasing confidence in their role and their ability to decide not to accept a referral.

By the end of the three years, there was a general consensus relating to a strict policy of referral. Referral must be based on a diagnosis of LVSD supported by an echo, though some nurses complained that GPs might not fill in the referral forms with all the information. Some cardiologists complained about inappropriate referrals by some GPs who might use the
HFSN service as a 'backdoor entry' for a quick echo, or refer any patient who is breathless without a proper clinical assessment (17: CLC 15). Following a local audit at Site 11, the lead cardiologist remarked on the under and inappropriate use of their (hospital based) open echo scheme:

*Basically, we found that our open access echo cardiography service was being used by a small minority of GPs in a small minority of practices…. Those that were using it most frequently were largely using it for patients who had a very low probability of having left ventricular systolic impairment. Lots of patients were referred with normal ECGs, who quite clearly had other explanations for breathlessness which weren’t totally, honestly revealed in the referral form. Large numbers of GPs did not use the service at all. (17: CLC 40)*

At the same time, others felt that this criterion excluded a significant number of patients with right sided heart failure who could equally benefit from the HFSN specialist input or people with milder impairment of ejection fraction but significant symptoms who might benefit from the holistic input of HFSN (15: CLC 23). Given capacity issues at a majority of sites, however, this obviously seemed an unrealistic expectation.

On the whole, the pattern of referrals as well as discharge policy within a particular area was determined by where the HFSNs were physically based and the network of relationships between cardiologists, HFSNs, local GPs and care of the elderly physicians and, at times, renal physicians. However, a majority of nurses continued to get the bulk of referrals from the cardiology base, though referrals from GPs had improved by the end of the study. Site 26 was different in that HFSN 67 had an issue regarding lack of support from the cardiologist and fewer referrals from secondary care. She was working full time but had a small caseload of 30 patients, whereas her colleague HFSN 66, who was working part time (3 days a week), was handling a larger caseload of 72 patients. The workload issues at this Site were attributed to historical East/West divide (and, as we know from first and interim interviews, interpersonal issues leading to a lack of communication across the two areas).

**Caseloads**

In Quarterly Monitoring reports the nurses reported seeing 5,151 new patients in a year, an average of 68 patients per nurse.

The interviews with HFSNs did not reveal what would be an ‘ideal’ or ‘optimum’ caseload for the HFSNs to manage. However, this was discussed and many perceived that about 50 patients were the most that could be safely managed by HFSNs:

*The PCT strongly believe, for some reasons they’ve plucked the figure of 65 to 80 patients on our caseload and they follow that through the community matrons. But because they’re new, they’re not carrying anywhere near that number. I think we all know that’s far too many to manage safely; it’s too much. If you’ve got reliant dependent patients it’s far too many. To us 50 to 55 is a comfortable number to manage safely. If you get 60 you start missing things, you know, it’s not good, it’s not a good number basically above 60. I think we’ve got to find a middle ground because some of the patients are fairly straightforward clinic patients that you’re just optimising care on to prevent admissions, whereas the others where you’re preventing re-admissions, they’re your meat and bones that you really do need to see regularly.*

[25: HFSN 8; Int2]

There is no evidence relating to caseload numbers and the effective and safe management of heart failure patients by HFSN services. However, these perceptions provide useful insights into the types of patients that HFSNs’ believe they impact on - that is with patients immediately post acute event and those with advanced heart failure - and the numbers they feel able to actively manage to ensure appropriate and timely interventions.
By final interview, a majority of the nurses were working at an optimal level of caseloads they perceived as manageable – 50-60 active patients – though some with higher caseloads of an average of 100 patients were ‘struggling’ to keep their ‘head above water’ often related to sickness, or nurses leaving and vacant posts not having been filled for a certain period of time. However, some nurses noticed slightly smaller workloads when more BHF and non BHF nurses were able to share the overall workload. (26: HFSN 3, HFSN 4). At site 26, HFSN 5 had started working part time for personal reasons, job sharing with another BHF colleague who worked across two areas, and felt isolated being based at a community hospital and was less than happy at the small number of referrals that trickled in for her with a small caseload of 20 patients on average. She felt that the reasons were historical, the referrals from GPs had not improved in her area despite her continued efforts to make herself known, making presentations, and being based within the community. Part of the reason was that there was no GP with a specialist interest, and part since the secondary care hospital (a Foundation Trust that wanted to keep a majority of their patients on their records rather than referred back into the community) had a non-BHF heart failure nursing service who ‘creamed off’ the younger and less sick patients and referred only those who were elderly, too sick to attend the clinic or at an end stage. This sense of competition rather than working in partnership with the secondary care based service, she felt, meant that the service was less than equitable for those who could benefit from a community service, and made her feel that, ‘I feel more like an elderly care nurse specialist’ rather than a HFSN. She was not perceived as being visible by some of the cardiologists at the hospital though felt supported by the CLC who was based at another area but was unable to resolve the issue as being internal to another area. She did not feel this was an issue that was appropriate to be raised at the Steering Group meeting. It was hardly surprising to note that she thought she would have been better off to be based within the secondary care hospital though working within the community.

At the same Site, another nurse (26: HFSN 6), in contrast, had 350 patients on her records since she was managing half a caseload of one of her colleagues who was away due to long term sickness, seeing 2/3 of the patients in clinics based within both secondary and primary care and 1/3 at home. The cardiologist did not think these patients should ever be discharged. Some of these patients were seen by her only once a year, very few requiring intense input. She felt very well supported by the cardiologist with special interest and secondary care HFSN team and had excellent MDT links across primary and secondary care. Her background being District nursing, she felt that she knew exactly which door to knock, knew some of the community nurses personally and that helped build good links across. She would ring up GPs with an excuse to chat about a patient, just to maintain contact. Consequently, despite shared issues of boundary maintenance with other professionals, she suggested a good model of communication (send a copy of letter to GP and other nurses involved, negotiate who is going in to the home for what and when with the GP, DN, CM and palliative care nurse) and interpersonal relationships, given the support of cardiologist, leading to efficient MDT relationships across the primary, secondary care divide – though some of the weak links were noted with care of the elderly and cardiology. Interestingly, 26: HFSN 6 said:

‘I do not feel inundated. At this moment in time, everything is manageable. It is a little empire that I have built and I am loving it!’

She was obviously someone who derived a high degree of professional satisfaction from the job and, like many others, was proud of the service she had set up.
Time management related to an active caseload varied depending on the geography and area covered by a PCT and number of nurses working within an area. However, rather than just the number of patients, the balance depended very much on how many sick patients needing higher/palliative care they might have at a point in time. In addition, the distance travelled by some to cover home visits put considerable demands on time. For example, some of the nurses would travel between 40-70 miles in a day during home visits, finishing work 1-2 hours late (11: HFSN 48; HFSN 49).

Hence, nurses were aware that some of their time and activities are difficult to monitor in terms of value for their time and money in improving the care for patients (HFSN 48, 49, 47). This has led some teams to be more proactive in rescheduling work routines and developing innovative practices. For example, a combination of clinics for more stable and mobile patients with home visits for the more unwell NYHA class III and IV is a common policy to deal with this issue. At the same time, some nurses, for example HFSNs 48 and 49, had innovative ideas such as:

i) rotating the clinics to provide a more equitable service for those patients living further away from the clinics and not having access to transport.

ii) work in pairs, share home visits and use more telephone triage of stable patients for follow up

iii) at site 26, one of the nurses (26: HFSN 6) was involved in piloting a telemetry service to support suitable patients

iv) at site 25, the nurses were running a day time telephone advice line five days a week with the help of their secretary who was experienced and said to have very good communication skills.

**Discharge from service**

HFSNs also had to address the appropriateness of discharging patients from their service when patients no longer required ‘active’ input from the HFSNs. This activity was particularly challenging for some of the HFSNs because they had not a previous position where they had been responsible for making a decision about discharge of a patient. In addition, many of the HFSNs described difficulties with discharging patients with a chronic condition who may have got used to the HFSN visiting and providing support:

> I don't know if I would want to discharge any of my patients because I don't know if you can discharge heart failure patients. But what I would like to do is have an active set and have a sort of dormant set in a sense that make sure in 6 months time they'd had all their bloods done and they were okay and whatever and if ever they felt they needed to call me, the emphasis would be on them but they would have that link. When you say to somebody, I'm discharging you, from my previous experience they feel that they're not getting that support. I've found after a couple of months with my patients they don't really need me that much but just to know that I'm there when they need me is enough to keep them going. [2: HFSN72; Int1]

However, discharging (or open self referral status as it is often called by the HFSNs) is important for management of caseloads:

> If they've been stable for about 3 months, or you know they're on maximum therapy, I'll discharge them back to their routine usual care... When I say to the patient, you don't need to see me on a routine basis anymore, they've still got my phone number and they can still re-refer themselves back, as well as the GPs. [17: HFSN 24; Int2]

However, HFSNs feel it is inappropriate to discharge patients with advanced heart failure who require palliative care input. The HFSNs will make appropriate referrals to other services but also feel that they should remain involved with care and management of these patients:
It is a hard one because you can always be there for support even though you’ve maximised therapy. But we do tend to discharge our patients once we’ve got them on maximum therapy, or the maximum they’ll tolerate. We’ve obviously provided all the education with that about self-monitoring and self-management of the heart failure and if they’re stable at that time we would discharge them back to the GP for their care. Obviously saying that they’re very welcome to refer them back into the service whenever is appropriate because the likelihood is quite high that they’ll need further input at a later date. For those that are towards end stage heart failure, 3 to 4, we wouldn’t necessarily discharge them but refer them to other services as appropriate, such as palliative care etc. Perhaps not have such an active input but be there to support colleagues with some things and the patient as necessary. [15: HFSN 59; Int2]

By third and final interview, it was clear that the discharge policies varied a lot between, as well as within sites depending on the historical MDT connections and confidence of particular nurses in GPs and community nurses who, according to NSF guidelines, are expected to follow up patients at six month intervals:

‘To be completely honest, we have come to the decision, where we said, the only discharge at present would be if they (patients) die! We are still using an inactive and active follow –up because we found, when we try and discharge patients, they just come back into system. We have to completely reassess them and we end up spending more time.’ [2: HFSN 72]

Part time nurses, at times, found it more difficult to discharge and a majority felt that they would have benefited from a more definite, objective policy related to discharge, ensuring equity of service for all patients. It was perceived as a matter of a learning curve and confidence in one’s own judgement in knowing about appropriateness of a discharge, persuading most teams to address capacity and caseload management issues (e.g. 22: HFSN 17, 18). Some of the cardiologists were concerned about the manner in which HFSNs seem to ‘hold on’ to patients, never discharging and creating huge caseloads not managed efficiently. Others worked constructively to outline a policy that provided guidelines. For example, one of the areas within site 22, HFSN 9 suggested that within the new service set up where there was none previously, they would follow strict criteria for discharge, using a dependency score, an open ended appointment for follow up at a surgery– making sure the necessary tests will be done, and a telephone follow up call in six months’ time. As noted above with regard to comments of HFSN 6, at Site 26, the cardiologist felt it was inappropriate to discharge patients. In rethinking a policy, she felt that younger patients who are stable and do not need much involvement and older patients who might not benefit from any more input from a HFSN should be considered for discharge. A majority of the nurses across sites followed an ‘open door’ policy to discharge where the patients were given their phone number and contact details and advised to ring if their condition deteriorated or they needed help with their symptoms. However, they also recognised that a majority of elderly, vulnerable patients perceived them as the first port of call and liked to have a chat about things other than their symptoms. Some of the nurses were more confident than others about the benefits of passing on some of their basic skills to GPs and practice nurses in taking care of the more stable patients within the community, both in terms of altering medications and protocol for follow up, depending on how good these links were in the first place.
2.2.2 Extending knowledge

In quarterly monitoring reports the nurses reported having carried out 5,280 teaching sessions for healthcare professionals over the three years of the evaluation. There is no information about whether these were one to one informal sessions or formal group education.

Some HFSNs express concerns about preparing primary care staff to manage heart failure patients who are discharged from the HFSN service. Many recognise that there is some way to go to provide education and support to primary care staff for their role in managing heart failure patients who require routine monitoring:

So that’s, I feel, very much my way forward, educating [primary care staff] to a different standard. Obviously I’ve got the specialist nurse title; I’m not expecting them to be the specialist nurse. But I am expecting them to have this structure to care for these people. And also for me to discharge to them or else I’m going to get overloaded. (26: HFSN; Int1)

However, an important aspect of the HFSN role is to extend knowledge on heart failure amongst the MDT to promote better management of heart failure patients. Many HFSNs expressed requiring a period of time to establish themselves in their specialist role and gain confidence in heart failure care and management prior to implementing training programmes for other members of the MDT:

You suddenly worry… in case they ask me something I don’t know the answer to. Because you’re supposed to be this person who knows everything about heart failure. You can’t possibly know everything. The job’s only been going for a couple of months. So yeah, it is a bit of a worry. (25: HFSN 7; Int1)

By second interview, many of the HFSNs felt that they had established their position within the MDT and were more equipped to develop other staff so that heart failure patients are supported in the community by a wider group of health care professionals who can draw on the HFSNs as required and for more complex cases:

We’re beginning to look at getting in more with practice nurses with getting them to manage the stable patients, you know. With the stable ones perhaps getting the practice nurses, they’re feeling a bit more confident now about up titrating medications and several practices are doing it, but not all. So we are just having the complex patients and again that makes it easier. (22: HFSN 17; Int2)

Delivering educational sessions in the community was proving a challenge for HFSNs because they needed to find time for this activity on top of their growing patient caseloads. There were also problems in the release of PCT staff to attend educational sessions because of financial restrictions in the PCTs. However, HFSNs in all case sites acknowledged the importance of this area of their role for ensuring that the MDT are better equipped with skills and knowledge so that the growing numbers of heart failure patients can be managed. The HFSNs will not be able to manage all heart failure patients and identify a clear role for others in education, support and drug titration, particularly of the less complex heart failure patients. A future role of the HFSN will have to be the management of more advanced heart failure patients (classified as NYHA 3 and 4) in their “active” caseload.

As observed by 25: CLC 30, it is unrealistic to assume a system where every GP (or practice nurse) within a pool of 500 GPs will be trained to manage heart failure effectively. This links in with the wider debate about the better value for money in HFSNs focusing on NYHA III and IV, GPs and practice nurses managing the stable I and IIs; the importance of using a preventative
approach and education for Is and IIs to slow their progression, and to what extent the specialist care can be shared and yet seamless and personalised.

**Effectiveness**

HFSNs discussed their contribution to treatment, management and care of heart failure patients and the ways in which they feel their inputs improve patient care. A main organisational aim of the HFSN service is to reduce hospital admissions for heart failure patients. During interview, the HFSNs were keen to distinguish between admissions to hospital which they could prevent (‘inappropriate’) and those which were planned and ‘appropriate’ for management and care of the patient.

A significant role for HFSNs is drug titration and management of patients’ medications to ensure patients receive optimum therapy. HFSNs from all case sites referred to their important role in providing education and support to patients and their carers about the condition and its management (lifestyle and medication):

I feel what I can give is slightly more than what the cardiologist can give, and that’s time. And I believe that these patients need a lot of time to explain, voice their concerns, because obviously it is a debilitating life threatening illness and I think these patients need a lot of psychological support. [26: HFSN 5; Int1]

He has been a revolving door type patient where he’s been in hospital all the time, and this is the first time he’s actually been picked up and followed up at home. I went through his medication with him and he was complaining of cold hands and feet and I said, I think you’re on a beta-blocker medication, let’s look through your medication and he said, I’m not on a beta-blocker my doctor said I wasn’t. And when I went through his pills he was on a beta-blocker. We went through lifestyle modifications, he was drinking things like lots of Bovril and stuff and just little things like that and his wife was quite happy. And he was like, Pet will you call again? I said I would leave him a few weeks and then call him but said contact us if you need to. He was really pleased. [26: HFSN 4; Int1]

As well as providing care to patients via home visits and clinics, the HFSNs all had telephone advice lines that patients and carers could utilise if they had any worries or concerns about the condition of the heart failure patient:

We’ve been giving all patients a contact number. Obviously if they’re unwell or anything, see their GP. But if they’re just not sure of something, we’ve given them contact numbers and people have been ringing us for advice which is good. [26:HFSN 3; Int1]

In one case site (11), two nurses are qualified nurse prescribers. The HFSNs indicated that this qualification made it much easier when needing to consult with medical staff about changes in a patient’s medication and ensures prompt management of the patients:

I’ve got one particular GP who I now do nurse prescribing with, which takes an awful lot off him. I just do a clinical management plan and then I go out and see the patient and just get them up on their ace inhibitors myself over a period of weeks obviously but each time just write to him saying, I’ve done this now and I’ve done this now. He loves it because he doesn’t have to see the patient once in that time. So the patient has got over a period of about 2 months, he’s had maximum drug therapy without having to see the doctor. It’s all done through me. [11: HFSN 50; Int2]

In some situations where HFSNs did not have prescribing rights, they experienced difficulties when liaising with GPs about medication changes in line with service protocols:

There is a little bit of hesitance when we actually ask them to do things. In certain areas we request GPs, because we’re simply following protocols that have been generated by discussion and from the consultants...
themselves, as to how the patient should be treated and how things should be up titrated in terms of drugs etc. Sometimes we ask the GP to honour this but they choose not to and very often we have to wheel out the consultant in order to overwrite the GPs… Sometimes they have a valid reason or sometimes it’s completely invalid and we have to bring out the consultant and say, well actually the consultant’s in charge of this patient and he insists that this patient is started on such and such a drug etc. [25: HFSN 52; Int2]

The majority of HFSNs felt the time they were able to give to patients really made a difference to patients for understanding their condition and being confident to self-manage it. In addition, the HFSNs emphasise their role in coordinating care for patients and carers by liaising with other health care professionals or service providers (such as palliative care team or cardiac rehabilitation services) to ensure heart failure patients receive appropriate care and management. The HFSNs emphasise their long-term involvement with patients to provide continuity of care for patients throughout the trajectory of the condition and especially during palliative care when the condition is advanced:

Although we might have been seeing some [NYHA] 3 and 4 in the secondary care clinic, when they got to a particular stage where it just wasn’t fair to bring them up anymore, you know, that was where your support started to lack because you couldn’t actually follow them properly. Whereas now when they enter their terminal phase we can still continue with other support from Macmilan and that and we’re learning more about how to actually support these patients. The strategies are out there for heart failure patients now… I think for the patient and family, that really is the time where they need that person who knows them inside out by that point because you do you often get a year, two years down the line and you know these people and they know you so that’s a massive improvement without a doubt. [25: HFSN 8; Int1]

At times the HFSNs’ perceived that because they were closely monitoring patients this led to timely and ‘appropriate’ admissions for patients:

I think on the flip side as well, we’re trying to prevent re-admissions but we are causing a few anyway just because of the fact that we are monitoring them so closely… A chap I went to see… this day I said, how are you feeling today Mr [name] and he said, I feel great, absolutely great. And I thought, right I’ll write that down, feels great. But as a matter of course I thought I would take his U&Es. And we got his U&Es back on the Friday afternoon and they were grossly deranged. So we had to arrange for his re-admission even though he [felt] fine. [HFSN 19: 1]

The HFSNs perceive that their activities are having a positive impact on patient care and reducing ‘inappropriate’ readmissions. However, they also recognise that they are part of a system of care that requires the involvement of many other members of the MDT. The HFSNs identify themselves as mediators of care boundaries, or the ‘conductors’ of care, to ensure that patients are put in contact with the appropriate services and managed across the primary-secondary care interface. The HFSNs are establishing relationships with a wide variety of members of the MDT including therapists (occupational therapists and physiotherapists), rapid response team, district nurses, practice nurses, GPs, cardiologists, consultants, palliative care, hospice staff, residential care staff, cardiac rehab, clinical psychologist, social services, community psychiatric teams, pharmacists, community matrons and voluntary agencies. HFSNs report that developing relationships with members of the MDT depends on patient caseload; contacts being made around and for patient care. HFSNs were also keen to emphasise that their physical location (or office
base) was key in influencing the development of relationships with the MDT. HFSNs located in hospital offices felt distanced from primary care:

> It feels like we’re a community team but in the wrong place if you like being based at the hospital. It’s just physically difficult. Rather than popping in to see a GP or popping around the corner to see the district nurses who are in the same building, we’re having to use the telephone or actually organise appointments to go and see them. So I don’t think we’re having as many opportunities to just bump into these people and get our faces seen. [25: HFSN 51; Int1]

HFSNs based in primary care settings were more likely to express feeling ‘part’ of the community team and that this had benefits for patient care because they can more easily liaise with colleagues:

> I’m based in a clinic. What we have is, we have all the specialities based in one clinic and we got the diabetic nurse specialist, tissue viability, we’ve got the cardiac nurses, we’ve got family planning, district nurses and health visitors, so it’s a core group of specialised nurses working in one place... We never used to be; when I first actually joined the team as CHD nursing team in the community we were actually quite isolated. We were in offices away from everybody. But I think the Trust saw the sense in actually putting us together because of some of the chronic diseases interlinking so much and I mean I’ve got the diabetic nurse specialists next door to me and I have patients who need referrals to them and it’s so easy. [2: HFSN 72; Int1]

The HFSNs recognise the importance of establishing networks to enable them to fulfil their coordinating role and over time gain experience to help them negotiate ‘barriers’ and ‘hurdles’ presented by health and social care services. As such, they perceive their specialist nursing role as having a small (but significant) contribution to the overall care and management of heart failure patients.

### 2.2.3 Equality of access to specialist care

HFSN services are part of specialist care services offered to heart failure patients and their carers. As a developing service, it is inevitable that there may be some inequities relating to who accesses these services. Importantly, mechanisms for referrals of patients will be a large influence on service use. In some areas, the ways in which patients were referred to the service narrowly focus the service to patients who are under the care of consultants or GPs who refer to the HFSN service or particular wards that the HFSN service has close links with. This leaves areas where some patients may not be given the opportunity of being referred to the HFSN service:

> GPs haven’t referred a great deal of patients to us and neither have they taken up the opportunity of the open access echo service. So it poses a question, whether there are quite a lot of patients in the community that haven’t been picked up yet. [25: HFSN 52; Int2]

> I think fairly recently we did an audit and I think it did come out of that that we’re probably not getting, well we know we’re not getting all the patients who would be eligible for our service through the in-patient wards... I don’t think we’re picking up all of them. So there is an issue about fairness in terms of providing a service to everybody with LVSD. I think certainly the cardiology ward is very good at referring through, we do get those through. So I think it’s probably more the general medical wards who perhaps our profile isn’t high enough for their understanding of what our service is and how it can benefit the patients; may not be a priority for them and they’re not actually thinking of us as part of their tick list of things to do before they discharge the patient. [22: HFSN 20; Int2]
A HFSN suggests:

I feel we’re scratching the surface of a great unmet need if you like. [26: HFSN 4; Int1]

HFSNs located in a hospital site suggested that their physical location may lead to some inequalities in the services offered to patients pre-discharge. It was suggested that where referrals came from two hospitals, the HFSNs were more likely to see patients pre-discharge in the hospital where they were located because of the distance to the second hospital. This was perceived to cause some inequities in service provision:

But then that’s something that’s going to be needed to be expanded really, because probably the [name hospital] patients are getting more the second-hand service perhaps and we’re neglecting them. [22: HFSN 17; Int1]

The HFSNs also highlight that geographical boundaries are causing inequities in service provision. The HFSNs are employed by PCTs; this means they only consult patients from within their PCT. In practice, this can create difficulties where there may be two heart failure patients in a hospital ward but because one does not come from their PCT they cannot provide a service, even though the patient will see other patients on the ward receiving the service. This creates difficulties for the HFSNs and unequal service provision from the patient’s perspective:

We’re still getting patients that don’t fit into the [name] PCT which is making life a little bit difficult. So we’ve opened up the service to the physicians and they then come with a load of referrals and we’ve gone, no. So like they’ve referred 5 patients in one week and we couldn’t accept them… I even think for the cardiologist that has been quite difficult because historically anybody who had heart failure who was in [name] hospital was picked up by the [secondary care] heart failure specialist nurse. But now it’s PCT owned and therefore only patients within that area can come into the service. [25: HFSN 7; Int1]

One case site described strategies for ensuring availability of the service to non-English speaking patients. HFSNs from this case site (anonymised to protect HFSN identity) describe the interpreting services that are readily available to them in the Trust and also the benefits of having a HFSN who speaks Hindi and Gujarati:

I think we’re improving access purely by me being able to speak Hindi and Gujarati. I have a lot of Asian patients and okay some of my patients that don’t speak Gujarati I would be able to get by with them in Hindu and even the Punjabi population. I mean my Hindi is not as nearly as good as my Gujarati is but I can actually communicate with them on a very basic level and they make an effort, and I make an effort, and I can understand a lot of their cultural needs and ethnic needs and as a result of that I’ve been able to do workshops in Gujarati and Hindi for them… That’s actually helped improve services as well, so that’s been quite good. [Anonymised]

In another area, a HFSN discussed exploring the needs of patients from a minority group:

Part of the area that I was working, before everybody else came into place, was the Asian community. I do have some patients within that community but not necessarily a huge caseload but next week I’m going in to a patient clinic which is specifically trying to develop services for that community. I’m actually looking to see how that service can develop in that area. [22: HFSN 20; Int1]

At second interview the HFSN explained that the PCT had no extra resources to help provide any additional clinics. Given the close proximity of these communities to the district general hospital the HFSNs had decided not to continue with, or further pursue, plans for a separate clinic. HFSNs from the other case sites did not discuss arrangements for patients from non-English speaking groups. In the main,
this was because they reported that they did not have these patients in their caseloads.

By the end of the study, whilst the nurses overall did not mention issues of access to patients and carers from minority ethnic communities as a significant issue, one of the cardiologists recognised the difficulties (22: CLC39) in providing adequate support, especially to those who do not speak English. Some of the nurses, however, suggested that South Asian patients might be under-represented in the service since they have adequate family support and may not want to see a heart failure nurse. These assumptions were based on anecdotal evidence of other services (such as cardiac rehabilitation) rather than first hand experience. We shall return to the implications of such assumptions for access to services in Chapter 3.

The organisation of services in one area was causing particular difficulties for HFSNs because they were integrating with NHS funded HFSNs who had different referral criteria compared to the BHF funded nurses. In this site, the BHF HFSNs were keen to ensure that they only accepted referrals of patients with LVSD. However, the NHS HFSNs accepted all heart failure patients. This was thought to lead to perceived inequity amongst the MDT:

We were categorically told by our consultant lead… only to take patients with LVSD, and those patients with right sided failure were not suitable for the service… [A consultant] referred [a patient] to me with clear right-sided heart failure… And it’s those kind of things when you’re starting a role, that you need to work within clear guidelines, and all those grey areas just make it more difficult. {17: HFSN 2; Int1}

Whilst HFSN services are endeavouring to provide a service to heart failure patients and their carers, initial and interim interviews revealed that some inequity exists in the provision of services due to organisational constraints and inadequate resources. This theme was continued at final interviews. One of the positive impacts of the restructuring of the PCTs was that the HFSN is addressing issues of equity related to residence since it covers wider areas and there are more HFSNs (BHF and non-BHF) on the scene. Inequity can, however, also arise from weak links and lack of referrals from GPs, elderly care physicians, renal physicians, or cardiologists. The relationships between BHF and non-BHF nursing teams have contributed to issues of inequity both in terms of referrals as well as policies of discharging stable patients into the primary care services. Some of the nurses felt that the policy of automatic referral (from secondary care) to a community matron following three successive hospital admissions implied that some patients with heart failure might not be referred to a HFSN unless heart failure is a major issue in their lives.

Apart from the generic issues related to advantages and disadvantages of being based within secondary care or a primary care site (clinical supervision and support, office space and secretarial support, service development) significant gaps in access to other services included access to cardiac rehab and psychological support (also observed by some of the cardiologists). Study site 26 was exceptional in that a consultant clinical psychologist (26: CPC 28) had taken the leads in addressing this gap by developing a network across different areas, providing training as well as support to the HFSNs in addressing specific communication issues related to caring for people with heart failure in general and those with palliative care needs in particular. Similarly, case study site 11 had a cardiac rehab nurse who provided separate sessions for patients with heart failure – in an otherwise overstretched rehab service where one rehab nurse took care of 400 patients (11: CRN 31, CRN32), providing grounds for a separate business case for cardiac rehab for people with heart failure. 11: CRN31 also observed that cardiac rehab training needs a specific module on addressing the needs of people with heart failure.
On the whole, HFSNs had figured out a directory of various voluntary sector organisations supporting carers. 2: HFSN 72, for example, found the Crossroads as a ‘fantastic’ organisation who provided that much needed few hours’ respite to the carers. Those with a background in secondary care, however, took longer in understanding how community and voluntary sector organisations worked and found the pace more frustrating. Those with a background in DN/ palliative care or community nursing had personal links and knowledge that made access to non-clinical and social care services easier. This surfaced again in how the HFSNs perceived the boundaries of their role in providing a model of ‘holistic’ care to both the patient and the carer, and the need to focus on clinical issues and perceptions of access to social services. For example, 25: HFSN 52 shared his dilemma related to one of his elderly patients whose wife, his main carer, was suffering from dementia and reaching a stage where she would not be able to look after him in his end stage of illness. He said, ‘I need to concentrate on him. I can’t deal with everything else that is going on around him’, suggesting limits to how far he was able to provide holistic care to both.

Whilst social workers as well as HFSNs acknowledged the generic issues of long waiting lists and slow response of social services (22: SW29), some nurses found the response of the social services to be discriminatory and reflecting a lack of knowledge and understanding about the complexity of heart failure as a condition. According to 2:HFSN 72, the recent cutbacks in social services and new system of charging was associated with a perception that HFSN and patients might be over-accessing social services, whereas she had to make a careful assessment of needs in each case rather than ‘offer everything’. As a case manager, she had to keep ringing them up and she obliged to ‘sell her case’ before getting anywhere and found that ‘disgusting’. Occasionally, you might find an empathetic social worker who understands the issues but in a majority of cases, you have to be very assertive, pushing your way ahead, speak to the manager to be heard. She felt like, ‘… an advocate for the patient’s needs. I will go to whatever lengths I need to but we have a real problem with social services’. Similarly, 25:HFSN 52 felt frustrated with accessing equipment and said that some of his patients, ‘… might be lucky to have cancer as well, at least they can get a wheelchair!’ He felt that all the rhetoric about the GSF and extending palliative care and a seamless service for people with non-cancer diagnoses matched poorly with the reality that, ‘… heart failure patients and end stage respiratory failure patients have access to nothing!’

### 2.2.4 Negotiating multidisciplinary boundaries

As far as the notion of holistic care is concerned different professionals had different takes on who is best suited to providing holistic care to people with heart failure.

25:HFSN 7 provided a good summary of the differences in skills within the triangle of nursing care with:

i) practice nurses providing the wider base of generalist community nursing

ii) district nurses providing task oriented, hands on physical care in the middle and

iii) community matrons, palliative care and HFSNs providing the top level of case management.
Whilst the community matrons were seen to focus on and be oriented towards non-clinical aspects of case management, the HFSN were perceived as being oriented towards clinical and holistic care. However, whilst they did case manage irrespective of the involvement of the CMs, the PCTs did not seem to perceive this to be so. In some areas, this was a thorny issue related to lack of clarity of the CM’s role and issues of boundaries (horizontally), at others there seemed better understanding of roles, communication and negotiation of these boundaries.

Mediating boundaries vertically, especially with GPs and in moving to be a nurse-prescriber provided an interesting picture. Given that the legitimacy of the HFSN’s role comes from within cardiology as the basis of the medical management of heart failure, recognition of their role and expertise (delegated) was easier to negotiate though interpersonal issues and difference of perception of their role within the vertical hierarchy of medicine did cause some anxiety in certain areas. This was reflected in the different or guarded attitudes some clinicians had to the idea of HFSN stepping into the world of prescribing. At the same time, those who perceived the shifting hierarchy as a positive change, acknowledging that junior doctors (and GPs) also make mistakes while learning, the HFSN would have a similar learning curve and needed to be supported.

### 2.2.5 Impact of changes within PCTs and moving ahead

At the mid term and exit interviews, the larger changes within PCTs contributed to the level of anxiety about the future of individual contracts as well as the development of the service. There was widespread speculation about whether the HFSNs would be able to hold on to their specialist title or whether the economic logic of practice based commissioning would lead to their role being subsumed within the generalist role of the Community matrons or whether they would continue to provide the same specialist service with a sub-title attached to the CM title.

While living with the uncertainty had made some cynical about the NHS in general, a majority took pride in their role and appreciated the excellent clinical training and educational support they had received from the BHF. They had found their specialist training and experience challenging and rewarding in terms of the difference, they believed, the service had made to patient care over the past 2-3 years. As suggested earlier, subtle differences between BHF, non-BHF and adopted nurses underpinned a distinct sense of identity related not only to their specialist skills but also a particular culture (set of values and practices) of care.

As reiterated by one of the nurses:

‘I think it is that issue about being very proud to represent the BHF and we are ambassadors for them and that’s what I said earlier, I like to wear the uniform’.

She continued later,

‘I am proud to be a BHF nurse and I don’t want to lose that’. (11: HFSN 49)

We conclude the section on this positive note since it reflects the overall mood of optimism and enthusiasm across the board about the BHF nurses, despite major changes and insecurities threatening their role and identity.
2.3 Interviews with the multidisciplinary team

The interviews covered three main themes:

a) remit/role of particular professional in relation to the HFSNs; looking at formal and informal support/training/skills provided to HFSNs and vice versa

b) working as part of a MDT team, networks across Primary, Secondary and voluntary sectors of care; looking at strong links and weak links/gaps within and across, local initiatives, and impact of recent changes within PCTs and future developments

c) impact of the presence of the HFSNs in providing better quality of care and access to services for patients; in supporting other professionals in providing better care to their patients. (We later discuss this as ‘added value’ to the service)

We shall now summarise the findings and their implications covered under these three themes. The first two themes are intertwined and hence are treated together to avoid repetition.

The role of particular professionals working across the Primary and Secondary care divide

All the HFSNs taking part in the study are employed by a PCT, hence ownership of the service, operational and strategic management lie within the PCT. The BHF co-ordinator for each site does not have responsibilities towards managing the nurses, though they are responsible for the overall co-ordination between different sectors at each site as a representative of the BHF. Day to day management and clinical supervision of the nurses has been a particular issue at certain sites due to quick succession of changes at managerial level, especially within the larger context of the merger of PCTs and subsequent uncertainty about the future of the service and contracts for the HFSNs, as the three year BHF funding came to an end.

The specialist background of the operational manager makes a difference to the level of day to day support received by the nurses, the personal and developmental goals set by the nurses within a particular team, and potential reconciliation of outstanding structural and interpersonal issues. For example, site 25, experienced particular issues with unsatisfactory line management of the HFSNs, resulting in a split in the Steering Group into clinical and line-management sub-groups (25: CLC30). This had an impact on the morale of the nurses as well as developmental goals of the service, as explained in the following excerpt:

…, who have big problems at the moment with management support and their line manager having recognition of their, actually, roles and the scope of their roles, scope of their responsibility. I think (this) has obviously proved very difficult for the nurses themselves and there was a clash there as well …. I think the nurses feel that the manager doesn’t have the level of knowledge and the skill to be able to manage them effectively as they would wish to be managed. So while yes, there are still providing a service to patients, I think, pushing those services on and developing new services, has been hindered quite a lot by that (25: HFSNL3).

The extent to which strategic/steering group and operational/sub-group meetings represent a cross-section of representatives across Primary and Secondary is a good measure of relationships and a sense of ownership and partnership within the heart failure service at a particular site. For example, at site 15, changes and moves within PCT led to a disbanding of the Steering Group for a year and a half (15:PCTL21). The CHD network, a key to multi-disciplinary relationships, did not seem to have any communication with Primary Care at a
strategic level for nearly two years, there being no GP with special interest to adopt the cause, resulting in gaps, especially in the primary care links and development of clinics based within Primary Care (15:PCTL21). The BHF nurses had to develop links at an individual level. This was in contrast with site 25, where a committed GP with special interest in cardiology was the PCT lead for CHD and chaired the NSF (sub-group) steering group meetings (following a split mentioned above). She was actively involved in clinical supervision, training and development of the HFSNs who had a base both within the secondary and primary care settings (25: GP27; 25: CLC30).

Conflicting perceptions of who runs and attends these meetings are rooted in more than mere interpersonal issues of dominant personalities pushing a particular agenda, going back to a particular history of the service and interdisciplinary links forged during the development of the service. As observed by one of the lead cardiologists:

*We have recently revisited the terms of reference for our heart failure subgroup to some extent because we were getting noises from primary care and from the heart failure nurses, the BHF nurses, that we weren’t responsive to them and that was in spite of all the nurses locally being invited to the strategic group meetings, many of them coming and invariably saying nothing then going away afterwards and complaining about what has happened. You can quote me on that because that’s exactly what’s happened. I don’t mind if anybody thinks that’s an inappropriate thing to say but that is exactly what did happen. So we proactively looked at the membership of the group—primary care was very variable in its representation. The line manager for the BHF nurses invariably didn’t come so
we revisited it to try and firm it up and say we expected that person to come and if that person wasn’t to come then a named deputy was to come, not 6 of the 8 heart failure nurses to sit there and say nothing (17: CLC15).

The diversity of a large pool of GP surgeries working to autonomous practices within a PCT was outlined by many HFSNs as contributing to their variable attitudes and inputs into the service. As suggested by 11 ID 80, for example, it would be unrealistic to expect a MDT meeting with Primary Care professionals (cf. impossibility of matching diaries), ‘They won’t come. It is hard even to get a GP to represent (them) on the HF steering group’; and you would need more than just one committed GP with special interest to forge the necessary links across a PCT, as suggested by 25: CLC30.

Different professionals weighed the advantages and disadvantages of the BHF service being based within the Primary Care depending on local links:

- mediating the Primary/Secondary care divide
- mediating different disciplinary perspectives
- mediating interpersonal issues

Whilst a majority of professionals across the board agreed that it made sense for the HFSNs to be based within the community services to achieve the aim of keeping patients out of secondary care, some (for example, 17: CLC15) disagreed and believed that that having a base within secondary care would ensure better management, supervision and efficiency. Hence, on one hand, the HFSN service (used interchangeably hereafter, ignoring the other, secondary care based model) fits well within the broader chronic disease management agenda, that is very much at the heart of recent reorganisation within PCTs. On the other, the clinical underpinnings of the HFSN service are rooted in cardiology and its base within secondary care, leading to the perception of the service being led by cardiology and cardiologists (a perception shared by a majority of HFSN who came form an acute care background). As reflected by one of the GPs (local lead for long term chronic conditions) in response to the different models of service operating within her area:

> I mean, the trouble is that one does not, sort of, see them as part of primary care team, and one sees them rather as an outside service…
> I don’t really see them as a primary care nurse…
> It’s seen very much like; it’s rather viewed as initiated through secondary care. (26: GP26)

The two nurses job-sharing at this area were based at a small community hospital with better links with the Primary Care rather than hospital based services. ID5, perceived the non-BHF heart failure nurses at the main hospital as blocking access for patients, by holding on to them. The GP maintained active heart failure register and was in close contact with the community cardiologist and community cardiology nurse, yet the number of referrals from GPs was quite small. As suggested by 26: GP26, among various other professionals, some GPs believed that they could manage heart failure themselves without the help of a HFSN, some preferred referring to a cardiologist rather than a HFSN in line with old hierarchy within medicine. For others, heart failure might, in fact, be a small portion of their caseload, 2-3 pts in a year, as suggested by 17:GP14 working in a remote rural area:

> Yes, and for example, the other patient I have in heart failure is also a palliative care patient, in fact we’ve managed him in the community but he got acutely short of breath overnight and in fact, so the heart failure nurse would not have prevented his admission.
> SC And was there any particular reason that this patient you felt wasn’t properly referred to a heart failure nurse?
> 17GP14 I think at the moment because I don’t, we’re at a distance from …., we don’t see much of the heart failure nurses and so
I’m not in such close contact and often they sometimes fall out of my awareness and I think if I had one, like a district nurse coming to the surgery or actively phoning me I would probably tend to refer more but I think there’s some pressure between them to actually get round to all the patients they are seeing.

According to one of the cardiologists, 11:CC40, the reasons why some GPs might not use the service can be complex and multi-factorial:

Yeah, it’s both, it’s about education and it’s about resistance to change. It’s also probably about communication. Some GPs just either don’t read things that come to them or things that go to the practice are read by the practice manager and not distributed to the GP. I think there are lots of different factors that will influence whether or not a GP will change his or her practice.

As noted by various HFSNs in their interviews, dealing with GPs is a different ball game, given the sheer number of practices and hundreds of GPs working within a particular PCT area covered by each nurse. Hence, each nurse needs to have a presence in the surgeries – getting to know the GPs personally, through examples of good work and training sessions and re-launching the service from time to time (11:HFSN 80). Some nurses felt that being round the corner from the GP (or cardiologist), and a face to face or telephone chat helped. Hence running or sharing a clinic alongside GPs at a community health Centre helps maintain good relations with GPs (2:HFSN 25), even when generic links between the two sectors are poor. Personal initiative of a GP with a special interest (GPSI), taking the lead in mediating can make a difference to the level of support and supervision provided to the HFSNs. Study site 2 provides a good example where HFSN 72 is able to run a heart failure clinic on her own at a health centre, where patients have access to a community cardiologist, echo, ECG, blood tests and other services (one stop clinic) normally provided in a hospital. There can, however, be significant variations in how the service is structured not only across but also within one case study site. Two other areas at site 26 operated with a different model where HFSNs had equally good access to both primary and cardiology and acute care based services, running clinics in conjunction with or supported by cardiologists with special interest in heart failure.

At some sites (for example, sites 17, 26), having BHF and non BHF nurses within two models of the service posed interesting tensions. These were observed in working relationships, perceived levels of efficiency, and the need for clinical and clerical supervision accentuating the divisions between primary and secondary care, rather than creating a seamless service across. The following remarks by a CLC at site 17 have to be placed within this context:

SC Is there an issue about them being based in primary care and working across and some of them seem to find it difficult to pinpoint where that particular resource comes from and where time is spent because they seem to be cutting across this division between primary and secondary care?

17: CLC15 I would accept that and I think part of that is probably due to a lack of a clear clinical lead in primary care for the (BHF) nurses. And I think, if you have the service based in secondary care with one or two senior clinicians who are the clinical lead, that immediately makes things more streamlined and clear. As I say, I think that in primary care, in reality, the nurse has to interact with each and every patient and individual GP and that’s a very variable feast…. I’m not necessarily saying we take them from primary care and move them into secondary care, no, but what I would do is give them an office to share in secondary care.

SC How do you see the future the next couple of years?

17: CLC15 I think with all of the things I’ve said,
and I’m a very motivated heart failure doctor, I think it’s increasingly difficult to support all these (BHF) nurses because (of) difficulties there are in engaging with, not just them but with primary care, and I think there’s a big danger that the service loses it’s way if direction is not given or allowed to be given, should I say.

SC But that’s the direction we’re moving in terms of boundaries to make it more of a seamless service across Primary and secondary care?

17:CLC15 But again, you know, I think that’s the theory I don’t think keeping the patient out of hospital leads to a seamless service. I think, it leads to patients being kept in primary care who may or may not be better off in primary care. I don’t think that’s seamless - I think that’s a barrier.

Clearly, issues of level of clinical support and effective management varied between and within sites reflecting structural links, key professionals with a special interest in heart failure as well as local initiatives as part of the CHD network supporting the role of HFSNs. One good example was site 15, where the lead cardiologist suggested (25: CLC30) that if he were to be involved in setting the service all over again, he would opt for a model where they worked within the community but were managed from within an acute Trust to provide appropriate level of clinical supervision and support. This was taking into account the fact that a majority of the HFSNs came from a secondary care background with specialised skills, yet the PCT managers treated them like primary care nurses, not appreciating their skills, expertise and training needs.

Special contribution of BHF nurses, adding value to the service

As suggested succinctly by one GP, the presence of HFSNs working within the community has immeasurably improved the quality of life for patients with heart failure by preventing ‘preventable’ admissions:

Oh, absolutely! I would have thought it was one of the most important aspects of that, I really do think they prevent emergency admissions, you know the planned admissions for tests and things will not change very much but they are fantastic at preventing emergency things…. My perception is that they are trained fantastically well and fully able to do that (manage medications with complex interactions. (2: GP35)

However, it is not easy to measure this impact on quality of life and even ‘preventable’ readmissions especially when the coding system is such a ‘dog’s feast’ that patients might be admitted for a number of reasons not identified as HF. Even the sceptics, who were not particularly convinced that HFSNs might be preventing readmissions, agreed that their presence was good for the patients who benefited from their specialist input at home (17: GP14). Whilst most cardiologists shared the perception that the presence of the HFSN made a huge impact on the quality of life of patients in terms of access to information about heart failure, life style advice and counselling, continuity of care and end of life care issues, some conceded that there wasn’t any ‘hard data’ to quantify this positive impact (17: CC17). GPs and cardiologists felt supported by the HFSN in that they were leaving their patients in safe, competent hands with someone who had developed a rapport with patients and had the time to discuss end of life issues with them (15: CLC23), as is clear from the following excerpt from the interview with Clinical lead, cardiologist:

SC: You talked about the other skills that they bring in, in terms of managing your patients, so what are those skills that are more useful to you (unclear)?

25: CLC30: To me, I mean, if I’m honest, the first thing that’s the most obvious that’s from a doctor’s perspective is the time spent up titrating tablets, in some respects that’s the most simple thing they do…. I mean just the fact that you get patients titrated on their
ace or beta-blockers and/or spiro whatever else from A to B is a lot quicker, it’s a lot more efficient and the patients have a lot more time to be told about possible side-effects, complications and therefore more likely to comply, especially with beta-blockers. So, I think, they do that really well and that’s a very important thing because most of the evidence for saving people’s lives and improving quality of life is about the drugs. And then, the second thing that they do for me, which doctors don’t do, is spend time just talking about the pathology, you know, ‘this is what it means’ and things about life, driving, sexual intercourse, all of the other stuff that might be affected - that doctors just tend not to have time for and not want to, you know, they’re not going to go there.

You know, if I’ve 10 minutes to see a clinic or at the most 20 minutes to see a patient in a clinic, by the time you’ve seen the patient, examined them, had a quick chat about your heart, it’s not very strong and we’re going to do this and that, the time is up. Whereas they are much better, they have more time to spend, much more time on education, information, support and become more of a sort of, friends is not the right word but, you know what I mean, just a support, a confidant for the patient as opposed to the doctor who’s a little bit separated, I think. So I think they get to know their patients and they go into the home and they just get a different view of the patient, that is totally different to the doctor’s...

Another MDT member said:

I think they can improve the quality of life over and above what a GP can – one because, as you say, they’ve got specialist training, two they’re able to cover aspects of HF self-control (management), exercise, environment general healthy living, rather than just popping pills; and thirdly they’re invaluable in later stages of palliative care. Having said that, like all specialist nurses, they’re protocol readers really, they’re guided by protocols and if they have cases that don’t quite fit into protocols then they run into trouble (11: CEC3 reflecting on their strengths and weaknesses).

Some of the cardiologists valued the input of the HFSNs as much for the patients as for supporting them in providing better care to their patients, as reflected in the following excerpt:

SC: From a clinician’s point of view do you think their input has improved the quality of care for your patients?

22: CLC39: Tremendously! They’ve improved the care across the board. We get patients who now have much better access to evidence based care for heart failure. I mean, the guidelines are very important because they have improved patients’ access to, you know, not only appropriate therapies particularly beta-blockers and ace-inhibitors, but all the therapies really. So, I think, we would be lost without them at this stage.

SC: And, of course, there is this big thing about broaching prognosis in heart failure? As you know, there is growing literature around that and it seems to suggest that clinicians are a little bit hesitant in terms of … from your personal experience do you think that’s the case?

22: CLC39: I agree. I think, it’s something that very rarely comes up with clinical contact with heart failure patients. And again, it seems to have been a big advance in certainly the patients that are clearly as out-patients and steadily deteriorating, the nurses are now able to start to bring up these issues before it becomes a crisis situation and I think they’re far better at it than we are… I think they have the time to do it and they’re probably better than the majority of doctors though some of us think we’re okay at it… I think, as physicians we still tend to wait until they’re very close to the end before we start bringing these issues up.

SC: Is that related to their training?

22: CLC39: I think certainly if you look at the
level, say of consultant, I think now heart failure nurses get far more experience in managing difficult heart failure than most junior doctors, really. I think they do and because admittedly they have a much narrower field obviously, junior doctors have a much wider field. But within the field of heart failure, most experienced heart failure nurses are much more experienced than the doctors on the wards for instance. So now we find that with in-patients, they’re often in to guide junior doctors when to start thinking about issues like end of life or at least allow it to be brought up on the ward rounds, you know. I think it’s based on own experience, they are very experienced after a few years in post.

Clearly, the cardiologist highlighted the role of training, experience and time as underpinning the specialist skills of a HFSN supporting busy cardiologists and junior doctors. Equally importantly, the BHF nurses provided regular contact and good communication skills, leading to better continuity of care, as reiterated by one of the cardiologists who worked in both the acute and community settings:

SC: You said about how the heart failure nurses are supporting actually your work with heart failure patients, could you just elaborate a little on that?

17: C17: Well, they’re monitoring the patients on a much more frequent basis which allows them to manipulate the therapy much more precisely and much more frequently. The problem that I have is that I’m only going to make medication changes every few months…

What they’re doing you see is they’re seeing the patients much more frequently. They’re monitoring the weight, take blood samples, to monitor renal function and doing it on a week by week basis. So, in other words, the patient is being micro-managed; whereas, I’m there just really more as a sort of (taking a) broad overview simply because I can’t see them as frequently as I would like…. So, the fact that they are seeing the patient much more frequently is hugely valuable, you know, and that can only be a positive thing really. When you’re making a change (in treatment) and you’re not going to see the patient for 4 or 5 months, in between, the patient could get re-admitted twice and often get re-admitted to a different hospital and people will change the medications all over again, they won’t liaise with me even though the patient is under my care. So some physician in another hospital will literally obliterate the medications and then you’re back to square one again.

So having the heart failure nurses is a link. If patients do get admitted to other hospitals, I’m alerted to it fairly quickly and I’m alerted to the fact that the medications might have been dramatically altered so I can address that as ordinarily it might be weeks and weeks.

I’ll have no correspondence from the admitting hospital they’ll send correspondence to the GP but not copy me in, so I’m in the dark.

Finally, on how to judge this added value to quality of care received by the patients, he said:

It’s like cardiac rehabilitation, you know, the audit data for cardiac rehab internationally and nationally is actually very weak but if you talk to patients, did you find it helpful? The vast majority would say, yes extremely valuable. But, you know, a lot of people want firm outcome data in terms of survival and all this sort of stuff which doesn’t particularly interest me, I think there are quality of life issues that are just as important and if we are improving quality of life and keeping people out of hospital then, as far as I’m concerned, the service is working.

The consensus, despite difference of opinion on how best to structure the service, being that the service has made a positive impact on:

i) supporting other professionals using a multidisciplinary approach to managing heart failure across acute and community settings
and a significant impact on quality of life for patients who are receiving better access to other services and much needed continuity of care.

As concluded by one of the PCT managers, ‘We would be lost without them’.

One of the cardiologists, specially trained in management of heart failure, summarised the positive contribution of the BHF nurses within the specific context of dealing with an elderly, vulnerable population often taken for granted; a fact that does not make heart failure a sexy or emotive subject:

It’s not as emotive. You’re elderly; you’ve a mean age of 74, who cares? You know, who cares if you’re isolated, lonely and who cares if you can’t walk and are debilitated, nobody does. People do care, clearly they do care but it’s just not high on the heart strings kind of budget.

(Later on the difference the presence of HFSN working within the community makes)

… understood how much of a role they do, not just in terms of keeping the titrations up but the huge difference they make to patients’ lives. Patients depend on [name], you know, she’s a family member. She’s a rock for them, she’s all sorts of things and for [name] I hope you could substitute any BHF nurse’s name because this is a huge support network for patients who need support, and these are predominantly elderly vulnerable people (26: CC19).

Clearly, from this perspective, a HFSN service based in the acute sector rather than out in the community defeats the purpose. To conclude, apart from a handful of sceptics, there was a consensus about the benefits to patients and support for medical and nursing colleagues provided by the HFSNs.

Summary and Conclusion

Service delivery

- Nurses reported using strategies for effective caseload management and maximising the use of available resources.
- The integration of HFSN services with existing services varies across PCTs. Nurses have learned to mediate across care boundaries.
- There is increased availability of heart failure care in the community, particularly due to home visiting by the HFSNs. This has been especially valuable to the frail elderly patient with complex needs, and reduced some of the inequalities in access by disadvantaged groups.
- There is limited availability due to variability in heart failure clinic provision and the fact that HFSN service hours are ‘9 to 5’.
- Nurses are widening availability through: use of support services (e.g. day care, cardiac rehabilitation); broadening the skill mix (using health care assistants to monitor, secretaries to keep in touch); and providing new services (such as a telephone advice line).

Referrals

- Most referrals to HFSNs come from consultants in secondary care.
- Cardiologist support of the service is vital for its success.
- There have been some difficulties promoting the service to GPs to gain primary care referrals.
- Nurses are now widening their referral sources to include nursing homes, therapists, and primary and secondary care nurses.
Caseloads

- There is still debate about the size of an ‘ideal’ caseload. Nurses suggested that an active caseload of 50 seems about right. Large caseloads are difficult to manage, especially with home visiting, and nurses can feel overloaded.
- Nurses are learning to discharge stable patients to ‘open self-referral’ status.

Effectiveness

- Nurses are preventing ‘inappropriate’ admissions to hospital.
- Close monitoring leads to ‘appropriate’ admissions.
- Nurses are co-ordinating care with other services for timely patient support and management.
- Continuity of care and being able to give time helps with the education and support of patients and carers about the condition, lifestyle and medication.

Equality of access

- Access relies on healthcare professionals’ awareness of the service.
- Some patients are not offered the service, leading to inequities.
- Where nurses are physically based influences uptake.
- There is some geographical inequity as not all PCTs have a HFSN service, so patients in the same ward of a hospital may have differing access to HFSNs.
- There have been some organisational constraints and inadequate resources to enable all patients to be seen.

Conclusion

HFSNs improved the quality and reach of care for patients with heart failure. Collaboration with key staff in primary and secondary care facilitates effective management and patient pathways.
Interviews with South Asian patients and carers: Issues of Equity and Access

The NSF for Coronary Heart Disease\textsuperscript{16} highlighted inequities in service provision related to ethnicity, gender, age and geography. It recommended access to long term social support within community, including palliative care, as an important measure for reducing preventable hospital readmissions and improving the quality of life for people with chronic and advanced heart failure.

The inequities faced by people of South Asian origin in terms of significantly higher incidence of CHD, younger average age at first admission for heart failure, greater socio-economic deprivation among people of Bangladeshi and Pakistani origin, and poorer outcomes as compared with their white counterparts are well recognised in literature and documented in the NSF on coronary heart disease. However, South Asian patients are under-represented in clinical trials on heart failure and we know little about the impact of the illness on quality of life of patients and their carers, or access to heart failure nursing service\textsuperscript{15}.

As explained in Chapter 1, we included face to face interviews with a small sample of South Asian patients and their carers in the sub-study since previous research experience suggested that a significant number of people from these communities might have been excluded from taking part in the questionnaire based study for various reasons. We mentioned earlier that a majority of the professionals and HFSNs who took part in our study did not seem to think access to services for ethnic minority patients was an issue. However, a trawl of the Athena database revealed there were 187 people of South Asian origin registered with the HFSNs (of whom a small proportion were likely to have died or be ‘inactive’ and not in regular contact with the nurses). It was surprising that none had taken part in the quality of life survey, even though we would expect about 1/3 to be able to read and communicate in English. Anticipating the needs of potential participants from this patient population, we had provided translated versions of the information sheets and response forms (in Urdu, Punjabi, Gujarati and Bengali) for those willing to take part in a face to face interview, but had no response. We contacted all the HFSNs who had South Asian patients on their caseload to find out whether they had handed out the information sheets to their patients. It wasn’t clear from their responses whether/ how many of them had followed the protocol and handed out the information.

We started again by sending out fresh packs and following up particular sites where the nurses had responded more positively.

We eventually recruited 31 potential participants, out of whom we interviewed 17, following a theoretical sampling strategy that would represent the diversity within the South Asian population in terms of ethnic and religious background, as well as socio-economic position. 11 participants were of Indian origin (eight men and three women between 53 – 69 years) and seven of Pakistani origin (five men and one woman between 49-80 years), speaking a combination of Punjabi, Gujarati, Hindi and English. Five opted to be interviewed in English, whilst another used a combination of Hindi and English. We were able to interview 11 carers (see tables 3 and 4), two of whom opted to be interviewed in English. Only two participants remembered being given a leaflet...
about the study, one of whom thought that it
might not be appropriate for him since it was
regarding research based at the York University
rather than the hospital. Despite our efforts,
we were not able to include any participants of
Bangladeshi origin. This reflects partly a smaller
population and a very small number on the
Athena database. However, given the issues
with recruitment generally, it seems that some
South Asian participants might have been
excluded by default.

A majority of the participants were NYHA status
11 and 111, while one was NYHA IV, and had
significant co-morbidities, especially diabetes
(for details, see Table 4). Participants came from
different socio-economic backgrounds ranging
from tiny council estate flats to detached,
suburban houses. As we can see, men were
over-represented even though we tried
recruiting equal numbers. This could simply
reflect a recruitment bias (who was approached).
In the absence of analysis of wider data sets, it
is not possible to comment whether this might
also reflect a gender bias in referrals to a HFSN
within this population. The younger average
age of the participants in the sample reflects a
younger population. None of them lived on their
own, and a majority lived either with dependent
and/or adult children or in close proximity to
adult children, reflecting different levels of social
support available within a household. While
the clinical implications of a younger age profile
of South Asians with heart failure have been
discussed in literature, the social implications
for support are less well known15.

We used a topic guide covering three main
areas for patients: i) health and well being ii)
levels of physical activity and iii) satisfaction with
specialist nurse service. Similarly, the topic guide
for carers covered the following three areas:
i) caring responsibilities and impact of caring
ii) health and well being and iii) satisfaction
with the heart failure nurse service. The guides
reflected the questions covered by the quality
of life survey, though the results can’t be
quantified or compared directly with those
of the questionnaire. All the interviews were
tape recorded (except one where permission
was denied and hand written notes taken) and
translated and/or transcribed as appropriate. We
used a constant comparative method to look at
the differences and similarities in experiences
by gender, age and socio-economic position,
highlighting the context within which ethnicity
might be salient. It is important not to treat
these findings in isolation as solely reflecting the
impact of ethnicity, and rather interpret these
in relation to the rest of the study as well as the
wider literature on heart failure and HFSN service.

Given the small sample, we make no claims
at larger generalisations outside the context
within which the findings are located. Equally
importantly, rather than describe the data
under each heading, we find it more useful to
look at the relationship between the three areas
and how that shapes individual experiences of
the services. Hence, individual or biographical
features, access to English, and socio-economic
position can mark significant differences in how
people within the same ethnic group perceive
the service and its benefits at an individual level.
At the same time, the structure of the service
itself is an important factor in determining who
has access to the heart failure nursing service
and the benefits thereof.

All patient names in these interviews have been
changed to ensure confidentiality.

At the very outset, we identify three main scenarios
of heart HFSN services, placed on a continuum.

**Scenario 1**

The first scenario was perhaps the ideal from
the point of view of the patients and carers,
since they had a South Asian nurse who spoke
a local language. However, this model works
only in areas with high concentration of an
ethnic minority population speaking one or
two regional languages – a model difficult to
sustain elsewhere.
The three patients where the HFSN spoke a local language had regular contact with the nurse and were very positive about her clinical as well as psychological support. For example Mr Bhatt, a 53 year old man of Indian origin, explained why the support of the HFSN was important for him:

Mr Bhatt: I have known ... (heart failure nurse) for a long time now. She is one of the best because she is always asking me how I am feeling.

SC: So what are the kinds of things she helps you with?

Mr Bhatt: Whenever I have problems – she says just ring me and talk to me. I have her phone and mobile. She has all the equipment. I go and see her at the NHS clinic. She put in 24 hour tape for me – referred me to the specialist.

SC: Has she helped you in understanding what heart failure means?

Mr Bhatt: She told me what the problems are, what is going to happen....

SC: Before you met her, did anyone else help you with understanding?

Mr Bhatt: Earlier, I used to go to the GP. The GP does not understand anything, he used to say, 'Take some Paracetamol, you will be fine. Nothing wrong with you.'... She has so many contacts with everyone. When I had a problem with my Digoxin, she arranged everything with the doctors, I went there, straight away they gave me IV Amiodarone, put me on tablets and I have been fine since. (She also helped him write a letter to the council to help him move from the council flat)

SC: Has your care been better since you met ... (HFSN)?

Mr Bhatt: Much better. I really appreciate what she does for me. She checks my BP, cholesterol, gets a blood test done and checks everything to make sure everything is all right. She puts my mind at rest. She gives me lot of good advice, which I really like....

SC: What kind of advice?

Mr Bhatt: She says, 'Stay calm, don't think too much, don't worry....' I have somebody to talk to (major issue). I can't talk to anybody else about all this – I can't talk to my friend (partner)

SC: Psychological support?

Mr Bhatt: I really need someone like (HFSN). I can't do without her. If she leaves or goes - they say this foundation (BHF) don't have money for HFSN – I will say, that is wrong - they are more helpful sometimes than the doctor.

SC: What makes them more helpful?

Mr Bhatt: When you go and talk to a doctor – or team – they don't know anything about me. They have to read everything, and after one or two hours, they get to know - wasting my time and their time. When I go and talk to ... she knows my story. She gets to the top of the list straight away.

That extract speaks for itself in terms of the difference in quality of life, and why both elderly and even younger patients might latch on to a HFSN for the excellent clinical and psychological support they provide to their patients, and the crucial role of continuity of care in their positive experience.

Scenario 2

The second scenario was particularly interesting since the South Asian patients were initially excluded from the recruitment process by the BHF team. We were informed that these patients were not in contact with a BHF nurse and had been in touch with a cardiac link nurse who spoke a local language. The assumption was that the cardiac link nurse was providing the same level of support and quality of care to the South Asian patients.

The rationale for setting an alternate service reflects professional attitudes about cultural difference and ethnicity. The team were guided by the assumption that South Asian patients would not access the HFSN service ‘due to language and cultural barriers’. This site has a significant South Asian population and the PCT managed a small grant to support an Asian link
nurse with a background in CHD, who worked as a main link for non-English speaking Asian patients to access cardiac and heart failure services. She was ‘given competencies by both teams to achieve her targets prior to being allowed to work with these patients’. At the time of recruitment, this cardiac nurse had moved on nearly a year ago, leaving patients without much contact or support (see details, Table 4). We eventually recruited 8 patients from this site, and interviewed five of these. The first thing that is striking within this scenario of a specialised service is that it is discriminatory by default – three of these five patients spoke English. The second important feature here is that these patients did not receive the benefit of a HFSN service in terms of drug titration and had to see either their GP or cardiologist for a change in medication. This seems to have a ripple effect on the general experience that participants had at this site except for one exception – Mr Chauhan, a 55 year old man of Indian origin.

Mr Chauhan spoke good English and was quite restricted by his heart failure and diabetes (NYHA111). He had been hospitalised twice following bouts of unconsciousness, and was eventually contacted by a HFSN who he found very helpful since she got her medications to the optimal level and supported him during a difficult phase of his illness that was pushing him to the brink of depression. Interestingly, despite the poor quality of life and severity of his symptoms, the HFSN had been able to optimise his medications for him to make him feel more stable and he appreciated having a designated nurse who understood what was happening to him and knew what to do. He and his wife owned an off licence shop that his wife ran. They lived with an adult son in a terraced house in a ‘rough area’. He led a very restricted life, largely confined to their sitting room in front of the television, leading a minimal social life:

> Well let’s put it like this, I can’t call this living life, I exist, you know. It’s like … you can’t do anything that you want to do. I mean when my granddaughter comes I can’t pick her up; you have to be careful about everything that you do. … I go out and walk about half way up the street before, not even half, I have to stop, about 50 yards at the most and then I have to stop.

His diabetes made things much worse:

> Because what it is like they say at the diabetic centre, they say you’ve got a jackpot and I say, what do you mean? They say, let’s put it this way, you’ve got a full house, you’ve got a heart problem, you’ve got blood pressure and you’ve got diabetes which is a chronic state, there’s nothing else you could have and he said, you’re still living so you should be thankful. Because my diabetic is quite [unclear], I have to take insulin 5 times a day, which is quite a big dose, but it doesn’t matter what I do, that’s the only way I can control it and that is only just barely controlled.

It is obvious from the following excerpt from his interview that his quality of life was very poor, pushing him to the brink of depression.

**SC:** Do you think it sometimes gets you depressed?

**Mr Chauhan:** It does get me depressed. It gets me really down. I sometimes wonder whether it’s worth it at the end of the day, is it worth [unclear] getting about with it. I’ve come to a stage at one stage where I nearly didn’t take all my tablets, I was so depressed and I said, I’m not going to take it.

**SC:** Why wouldn’t you take your tablets?

**Mr Chauhan:** Well either way if I didn’t take my tablets it will either kill me because without those tablets it won’t improve my condition. I was just down.

**SC:** When was that?

**Mr Chauhan:** Last year.

**SC:** So what [unclear] got you back on track? Did you talk to your GP about it or to your heart doctor?

**Mr Chauhan:** I did talk to my GP about it.
SC: And what did he say?

Mr Chauhan: I just told him what was going through my mind, I said, I'm going to jack it all in, that's the way I feel. I've got a good GP, he had a word with me and he said, there is always something that is going to come up. At the end of the day he said, they'll be a cure [unclear] you've got to hang in. The same as Dr [name] told me, he said, I'll find a cure one day. He won't do the by-pass at the moment because there's too much damage on my heart. I've got too much muscle damage.

Mr Chauhan had been in contact with his HFSN for the past 18 months:

She tried to juggle quite a lot of my medication. They got some of it right but the problem is Dr [name] said I'm not a god, I can't control everything. He said, what's one body, what's one person's body the other one is different. But they got it up to a point where it's not so bad. At least I get about in the house and I'll stand a little bit in the shop, I help around the house and that's it.

He appreciated the help of the HFSN since she understood what was happening to him and what to do. He said:

I feel as though sometimes there's somebody there to help me and if I need them I've just got to make a telephone call and somebody will be there, if it's not [name] it will be somebody else.

The heart failure nurses they explain to you things better and they get to know what your symptoms are, how you feel because they see you quite a lot when you first start going there and then it eases off but they know how you feel.

He had obviously developed a sense of poise despite the poor quality of life and did not imagine life otherwise:

IF is a very big thing, you know, I understand that. There is no such thing as IF I did that, you know, we'll be wondering all our life. I would have been a different person if I did this.

It is interesting that Scenario 2 relates to an area with a higher proportion of ethnic minority population of whom the South Asians are a majority. There are interpreting services available and the NHS workforce is ethnically mixed. Yet, this was the area where the South Asian patients seemed to have received a second class service since they were excluded, by default, on the basis of their ethnicity and treated as being different. It is not, therefore, surprising that 2 of the 5 patients interviewed at this site shared their concerns about non-white patients being treated in a discriminatory way. One of these was a 65 year old man of Indian origin who was relatively well (NYHA II) and spoke from his wider experience of work and social life. The other was a 55 year old man of Indian- Sikh origin, NYHAIII, Mr Singh, whose mobility was limited due to obesity, had severe symptoms and was very unhappy about the quality of care he had received within the NHS.

Mr Singh lived with his wife and two children, one of whom was at the University. The family was under financial strain since he had to give up work as a lorry driver. He had been waiting for a treatment plan and nobody had explained to him what was going to happen or offered support. He also had specific religious issues related to surgery that he wished to be addressed, and felt that covert racism was part of the answer to how he had been treated. He was able to communicate in English, and yet felt that, ‘as soon as they see an Asian face, they assume you did not speak English – it works in subtle ways, they don't show it though. Despite the severity of his illness, and poor quality of life, the last contact with the cardiac link nurse and clinic visit was in 2005, a fact that speaks for itself. We have this information from the Athena database provided to us by the team.

**Scenario 3**

The third scenario surfaced in areas with significant proportion of South Asian or /and other ethnic minority populations, where patients had regular clinic based contact with
the HFSN who liaised with the cardiologist and the GP. As far as language support was concerned, in theory, the HFSN had access to an interpreting service through the NHS Trust. However, in practice, interpreters were rarely used. Even though this was not described as a major issue by the patients themselves, some of whom preferred a close family member rather than a stranger interpreting for them, this had obvious implications for the level of information and understanding the patients and carers had about the condition. It seemed that for South Asian patients of roughly similar socio-economic background, especially those who spoke little or no English, HFSN’s input remained minimal and largely focussed on up titration of medication and crisis management rather than psycho-social support and ‘holistic care’. Some of these patients might have received advice on diet and fluid intake from another service, for example, diabetes clinic and nobody had explained the significance of measuring their weight regularly. This led to a complex picture of how different individuals made sense of heart failure, given other chronic conditions, and how they perceived the significance of the input of their HFSN. We provide a few examples to unpick this complexity.

Mr Azhar, a 58 year old man of Pakistani origin, lived in a terraced, council house with his wife and two unmarried daughters (he refused permission for the interview to be recorded). He used to work in a factory but had stopped working due to failing health. He had diabetes, IHD, moderate to severe LVSD and NYHA 11 heart failure. He had been in regular contact with a heart failure nurse at the clinic for up titration of medication but had not provided any information on the condition and how to deal with it generally. He said that even though his condition was stable his symptoms were the same. It is hardly surprising that he did not feel that input of the HFSN had made any difference to his condition.

His wife, who had moved to England when she was a young girl, spoke better English but was not able to read or write English or Urdu since she never went to school. She was diabetic and hypertensive and not able to accompany her husband during every hospital appointment due to her other responsibilities. She had not had any personal contact with the HFSN or information about his heart condition specifically. Like some of the other carers in a similar situation, it seemed that she had not benefited from the input of the HFSN, even though she seemed confident about her English and understanding information passed on by the professionals.

Let us compare the situation of Mr Azhar with that of a slightly younger patient, Mr Azam, a 51 year old man of Pakistani origin who lived in a middle class end of the same area. His son was a dentist and his wife, who had moved from Kenya, spoke good English and was very closely involved in his treatment and hospital appointments. They owned a garage where he was actively involved at the time despite having significant symptoms. He had NYHA 11 level of heart failure and IHD, hypercholesterolemia and hypertension. His symptoms of breathlessness and dizzy spells and tachycardia had been worse in the past couple of months and he had had one hospital admission in between. Both he and his wife knew the HFSN and felt that she...
had been a great help in explaining the illness and how to take care of him. He had the same nurse as Mr Azhar but felt that she had made a huge difference to how he managed his illness. In fact, his wife said that he had started taking his medicines regularly since they visited the HFSN. Asked what the HFSN did for them, she replied:

Mrs Azam: She is a heart nurse and she treats him and she asks him about everything. She checks all the medicines and, if required, she increases or decreases his dose. She looks after him well and we are happy with her.

SC: Apart from medications … what about any other information about food, diet, such as what to eat and how much water he should drink. Sometimes they tell you about weight, how often to check it and how much it needs to be …

Mrs Azam: She told us about that. When she changed his medicines, she said that he was gaining weight. She said, ‘If you are having breathing problems, it means your weight is increasing. We do check his weight. We have got a scale and she also prescribed water tablets for him. When he needs to, he can take the water tablets.

SC: As you said, since you started visiting this nurse, you feel much better (confident about his condition). In what way do you find it better?

Mrs Azam: Things are better because my husband has started taking his medicines regularly.

SC: Do you think that is to do with how she explained the importance of taking his medications or what will happen if he stops taking these?

Mrs Azam: She told him that if he does not take his medications, his heart condition will get worse. If he takes his medicines, he will stay well and stable.

Mr Azam thought the HFSN was ‘better than the doctor’ and was particularly happy to attend the HFSN clinic at the hospital since they had all the equipment there and the HFSN was able to organise various tests and send follow up appointments so that he got various tests done in one day. This provided continuity of care:

Yes, the doctor who gave me an appointment was there and HFSN was there too. She gave a card to have these tests done and she suggested that she would ask them to fit a 24 hours blood pressure monitor as well. That time they did not have a blood pressure monitor available and said that an appointment will be sent to me to have this blood pressure monitor fitted in. We have received an appointment after that to see them on 22nd of this month. She does not keep you waiting … if something needs to be done, she will make sure that it happens straight away. I feel much happier that instead of visiting the hospital several times she makes it happen at once.

Mr Azam emphasised that he was not one to dwell too much on his illness and appreciated that the HFSN was positive in her approach.

Mrs. Anjum’s attitude to her illness sat somewhere in between the two examples provided above. She was 52 years old and of Pakistani origin, and had diabetes, cardiomyopathy and NYHA 11 level of heart failure. She was not able to tolerate maximum dosage of medications due to dizziness and even though she seemed restricted in her activities by her symptoms, she said that she was reasonably stable. Also, whilst she said that her HFSN had explained her condition in detail – she found it difficult to comprehend her symptoms and did not know what her ‘head had to do with her heart’ (referring to dizziness), and why she had the heart problem in the first place. Her daughter-in-law was a medical representative and accompanied her during hospital visits, she herself clearly avoided finding out too much detail so as not to get anxious. She said that she did not weigh herself regularly since she did not want to know if she was gaining weight and be worried about her weight. Instead, she ate healthily and was careful about getting some exercise. One could easily attribute her attitude to her ‘culture’ – except that this attitude reflects a wider coping strategy used by many white patients.
Mr Magbool is a 49 year old man of Pakistani origin with seven children and his wife did not seem to have received much support for the various issues raised by his illness, stroke and impact on social life. Nobody had suggested psychological help or counselling though the couple believed that it would have been a great help. The wife was suffering from depression for which she had been prescribed medication by the GP. He spoke good English though his wife could not and it seems that English, at least for him, was not an issue. We have to bear in mind though, that despite the impression that the psychological needs remaining unaddressed by professionals in such case, lack of access to psychological support and rehab for people with heart failure was recognised as a major gap in the MDT interviews.

In most cases, the needs of the carers remain unaddressed, as pointed out by one carer who wanted someone to explain her husband’s illness and treatment to her. This was arranged at a clinic visit, following our feedback. This does not seem to be a result of lack of access to interpreters since even in other cases and areas, where lack of access to English was not an issue; perceptions of professionals about family can lead to lack of referral to other services and support that might otherwise be offered to white patients. More proactive carers who speak English can, however, in some cases, build up a rapport with the HFSN and feel that they are more involved in the interaction with professionals, as we learnt form the experience of Mr Azam and his wife.

**Summary of main findings**

- On the whole, the needs and experiences related to heart failure, and the benefits of the HFSN service, are similar for the minority ethnic participants and the White participants who took part in the larger survey.
- More than gender, perhaps, the socio-economic background and ‘social capital’ (i.e. access to English and alternate sources of information) mark internal differences within each group.
- We found three main scenarios or models of service provision in three areas resulting in qualitatively different levels of access to HFSN services.
- We found examples of good practice suggesting that it is possible to provide an equitable service to people of ethnic minority backgrounds, given the commitment and leadership within local teams.

**Conclusion**

There are no essential cultural or religious features of any of the South Asian groups represented within our sample that might underpin their whole experience of heart failure and the HFSN service. More than gender, perhaps, the socio-economic background and social capital i.e. access to English and information, mark internal differences within each group. Our analysis of the three scenarios suggests that it is possible to provide an equitable service to people of ethnic minority backgrounds without pre-defining their needs as special or different. At the same time, one of the important findings from this work suggests that even where the resources are available, stereotypical assumptions about ethnicity and difference can structure services to exclude patients and carers who are from minority ethnic groups in a manner that leads to neglect and feelings of discrimination.18,15.
Chapter 4

Service impact on Health Related Quality of Life and satisfaction with care

4.1 Recruitment for Quality of Life and satisfaction with care survey

Questionnaires recording patient and carer quality of life and satisfaction with the heart failure specialist nurse services were given to patients at baseline, 6 months and 1 year. Patient and carer recruitment packs were distributed to nurses in all PCTs and were handed out by nurses with a patient caseload. The consenting of patients and carers was co-ordinated by researchers from the University of York.

Our aim in the survey recruitment was to gather consent from 700 patients and 144 carers with the intention of following up 500 patients and 100 carers at 12 months. Recruitment targets were exceeded with 954 patients and 342 carers consenting to complete the survey. Recruitment rates are detailed in figures 1 & 2 below.

Figure 1. Patient recruitment rate by month.
During the course of the survey period, January 2005 to September 2007, 157 patients died and 77 carers withdrew as a consequence of patient death. A full flow chart of patient follow up is detailed in figure 3. Of the 954 patients recruited 801 (84.0%) and 729 (76.4%) were successfully followed up at 6 and 12 months respectively. Of the 342 carers recruited 244 (71.3%) and 255 (74.6%) were successfully followed up at 6 and 12 months respectively. The aims of the survey recruitment were achieved.

Figure 3. Flow chart of patient survey recruitment. Recruitment rates varied between PCTs (Appendix 2)
4.2 Health related Quality of Life and satisfaction with care: Patient Survey

Data relating to the heart failure nurse caseload was compared to the participants in the patient survey on a number of key variables. The analysis provides an indication of how similar the patients completing the survey are when compared with the routine heart failure nurse caseload. The data was analysed using SPSSv14. Continuous variables are analysed using independent t-tests and categorical variables using chi-square tests. The results of the comparison are presented in Table 1.
<table>
<thead>
<tr>
<th></th>
<th>HF Nurse Caseload N=9354</th>
<th>Survey Patients N=954</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>71.9 (12.1)</td>
<td>71.7 (11.1)</td>
</tr>
<tr>
<td>Mean number of HF nurse visits (SD)</td>
<td>7.9 (6.2)**</td>
<td>11.5 (11.0)**</td>
</tr>
<tr>
<td>Mean number of readmissions (SD)</td>
<td>0.8 (0.1)</td>
<td>0.7 (0.1)</td>
</tr>
<tr>
<td>Mean number of nights readmitted (SD)</td>
<td>17.3 (3.9)</td>
<td>14.7 (6.5)</td>
</tr>
<tr>
<td>Source of referral %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiology ward</td>
<td>24</td>
<td>21</td>
</tr>
<tr>
<td>Cardiology clinic</td>
<td>37</td>
<td>42</td>
</tr>
<tr>
<td>Cardiology dept</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Other ward</td>
<td>10</td>
<td>7</td>
</tr>
<tr>
<td>Other clinic</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>GP</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>&lt;1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Palliative care</td>
<td>&lt;1</td>
<td>2</td>
</tr>
<tr>
<td>NYHA Class %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Class I</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Class II</td>
<td>45</td>
<td>51</td>
</tr>
<tr>
<td>Class III</td>
<td>39</td>
<td>38</td>
</tr>
<tr>
<td>Class IV</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>96</td>
<td>98</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Black African</td>
<td>&lt;1</td>
<td>0</td>
</tr>
<tr>
<td>Black Other</td>
<td>&lt;1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Indian</td>
<td>2</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Pakistani</td>
<td>&lt;1</td>
<td>0</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>&lt;1</td>
<td>0</td>
</tr>
<tr>
<td>Chinese</td>
<td>&lt;1</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Comorbidity (Asthma, COPD, Diabetes, Arthritis, Hypertension)</td>
<td>65**</td>
<td>17**</td>
</tr>
</tbody>
</table>

* significant at the 0.05 level  
** significant at the 0.01 level
The heart failure nurse caseload and survey patients were similar in terms of age, number of readmissions, nights readmitted, referral source, NYHA class and ethnicity. Significant differences were observed for the number of heart failure visits with the survey patients receiving more visits (11.5 vs. 7.9; p< 0.01) and having a lower proportion of people with at least one co morbidity (17% vs. 65%; p <0.01).

**Analysis of patients not approached for participation in the survey**

Of all those patients approached, non-participation forms were received for 267 patients who either failed the inclusion or eligibility criteria or were considered unsuitable for the survey by the heart failure nurse. Reasons for non-participation are detailed in Table 2.

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Number of patients N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No confirmed heart failure</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Does not live in community</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Does not accept service</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Eligibility criteria</th>
<th>Number of patients N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive deficit</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Unable to make decisions</td>
<td>9 (3)</td>
</tr>
<tr>
<td>In residential care</td>
<td>17 (6)</td>
</tr>
<tr>
<td>Not stated</td>
<td>29 (11)</td>
</tr>
<tr>
<td>Patient refused study pack</td>
<td>109 (41)</td>
</tr>
<tr>
<td>Nurse did not give study pack</td>
<td>85 (32)</td>
</tr>
</tbody>
</table>

When the population of non-participants was compared with the population of participants, non-participants were more likely to be older (78 vs. 72 years), more likely to be male (49% vs. 30%) and more likely to have more severe heart failure (65% vs. 43%).
Comparison of patients who consented to take part in the survey and those who did not

A total of 1023 patients completed and returned the baseline survey. Of these, 954 returned their consent form to take part in the study and 69 did not. There were no differences between those who consented to take part and those who did not. A comparison of those who consented to take part and those who did not is presented in Table 3.

<table>
<thead>
<tr>
<th></th>
<th>Consent (n=954)</th>
<th>Non consent (n=69)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Male</td>
<td>70</td>
<td>60</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>72 (10.8)</td>
<td>72 (11.1)</td>
</tr>
<tr>
<td>Self-care behaviour</td>
<td>22.2 (7.9)</td>
<td>22.4 (8.8)</td>
</tr>
<tr>
<td>(12 – 60; 0 = better self care)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minnesota Living with Heart Failure (0-105; 0 – Fewer problems)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall score</td>
<td>50.6 (24.6)</td>
<td>47.4 (27.0)</td>
</tr>
<tr>
<td>Physical dimensions</td>
<td>24.1 (11.3)</td>
<td>23.0 (13.0)</td>
</tr>
<tr>
<td>Emotional Dimensions</td>
<td>11.7 (7.6)</td>
<td>10.6 (8.2)</td>
</tr>
<tr>
<td>SF12 Quality of Life (0 – 100; 0 – Poor, 50 population mean)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical health</td>
<td>27.7 (7.6)</td>
<td>27.6 (6.8)</td>
</tr>
<tr>
<td>Mental health</td>
<td>45.1 (12.7)</td>
<td>44.5 (14.6)</td>
</tr>
<tr>
<td>Hospital Anxiety &amp; Depression (0-21; 0 low)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>9.0 (1.6)</td>
<td>9.0 (1.6)</td>
</tr>
<tr>
<td>Depressions</td>
<td>7.9 (1.7)</td>
<td>8.1 (1.7)</td>
</tr>
<tr>
<td>Borderline cases (HAD &gt; 8) %</td>
<td>86</td>
<td>84</td>
</tr>
<tr>
<td>Anxiety</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Depression</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Confirmed cases (HAD &gt; 11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Depression</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 3. Comparison between consenting and non-consenting survey patients.
**Analysis of survey responses for patients at baseline, month 6 and month 12**

Analysis was conducted for all patients who completed the survey at baseline, 6 and 12 months, because of this the values reported may differ slightly from those reported in Table 3 which includes all patients. Analysis was adjusted for baseline variables using analysis of covariance. We also explored the potential impact of a number of variables on the change observed over the survey period. These variables were age, severity of heart failure and whether the patients had any other illnesses that may impact on the outcome. Results of the analysis are reported in Table 4. (See page 65)

**European Heart Failure Self-Care Behaviour Scale**

The European Heart Failure Self-care Behaviour Scale (EHFScBS) was a questionnaire completed by patients when they entered the study, and again at 6 and 12 months after entering the study. The questionnaire measures certain activities patients should engage in as part of the process of looking after themselves and their heart failure. The measure provides an overall score ranging from 12, very good self-care, to 60 very poor self-care.

At the start of the survey the average score was 21.2 (standard deviation, SD 8.0) indicating relatively good self-care, at 6 months this had increased by 2.0 to 23.2 (SD 7.7) and at 12 months by 2.7 to 23.9 (SD 8.1). Overall patients’ self-care got worse as time progressed (Figure 1).

![Figure 1: Overall self care of heart failure scores at baseline, 6 and 12 months.](image-url)
At 6 months and 12 months small decreases in patients’ knowledge about how to look after themselves were observed. The patients’ knowledge regarding what to do if they get short of breath, to weigh themselves, if they gain weight, to limit the amount of fluid they consume, to take rest, what to do if they feel fatigued, to reduce their salt intake and continue to take medications all decreased by a small amount. Patients’ knowledge about getting a flu shot annually and taking regular exercise increased. It is worth noting that the population were already, at the beginning of the survey, quite knowledgeable about self-care of heart failure and the changes observed throughout the survey were very small. Changes for individual items are presented in Table 5.

<table>
<thead>
<tr>
<th>Item</th>
<th>Baseline mean (SD)</th>
<th>Month 6 Mean (SD)</th>
<th>Month 12 Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care items (range 1 – 5; 1 good self care, 5 poor self-care)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I weigh myself every day</td>
<td>2.0 (1.4)</td>
<td>2.4 (1.4)</td>
<td>1.5 (0.9)</td>
</tr>
<tr>
<td>If I get short of breath I take it easy</td>
<td>1.4 (0.7)</td>
<td>1.4 (0.8)</td>
<td>2.1 (1.4)</td>
</tr>
<tr>
<td>If my shortness of breath increases I contact my doctor or nurse</td>
<td>1.9 (1.3)</td>
<td>2.0 (1.4)</td>
<td>2.0 (1.3)</td>
</tr>
<tr>
<td>If my feet or legs become more swollen than usual, I contact my doctor or nurse</td>
<td>1.8 (1.3)</td>
<td>1.9 (1.3)</td>
<td>2.4 (1.5)</td>
</tr>
<tr>
<td>If I gain 2kg in 1 week, I contact my doctor or nurse</td>
<td>2.1 (1.5)</td>
<td>2.2 (1.5)</td>
<td>2.2 (1.3)</td>
</tr>
<tr>
<td>I limit the amount of fluids I drink</td>
<td>1.9 (1.2)</td>
<td>2.1 (1.3)</td>
<td>1.8 (1.2)</td>
</tr>
<tr>
<td>I take a rest during the day</td>
<td>1.6 (1.0)</td>
<td>1.7 (1.1)</td>
<td></td>
</tr>
<tr>
<td>If I experience increased fatigue I contact my doctor or nurse</td>
<td>2.4 (1.4)</td>
<td>2.5 (1.4)</td>
<td>2.5 (1.4)</td>
</tr>
<tr>
<td>I eat a low salt diet</td>
<td>1.7 (1.1)</td>
<td>1.7 (1.1)</td>
<td>1.7 (1.1)</td>
</tr>
<tr>
<td>I take my medication as prescribed</td>
<td>1.0 (0.5)</td>
<td>1.1 (0.5)</td>
<td>1.1 (0.5)</td>
</tr>
<tr>
<td>I get a flu shot every year</td>
<td>1.5 (1.3)</td>
<td>1.4 (1.2)</td>
<td>1.3 (1.0)</td>
</tr>
<tr>
<td>I exercise regularly</td>
<td>2.5 (1.4)</td>
<td>2.5 (1.3)</td>
<td>2.4 (1.4)</td>
</tr>
</tbody>
</table>

Table 5: Changes for individual items for the self-care of heart failure at baseline, 6 and 12 months.
Minnesota Living with Heart Failure

The Minnesota Living with Heart Failure questionnaire aims to assess how much heart failure prevents patients from living as they want. The questionnaire allows three individual scores to be derived: an overall score indicating the impact of heart failure on an individual’s life, an emotional score indicating the impact of heart failure on emotional aspects of an individual’s life and a physical score indicating the impact of heart failure on physical aspects of an individual’s life. Higher scores indicate a greater impact of heart failure on the individual, that is, it prevents the individual doing things that they want to do. A higher score indicates more limitations due to heart failure.

Over the course of the survey period reductions in the impact of heart failure were seen for all dimensions of the Minnesota Living with Heart Failure scores. The overall scores reduced from 48.8 (SD 24.4) at baseline to 45.9 (SD 24.3) at 6 months and 44.3 (SD 24.2) at 12 months. The physical dimension reduced from 23.2 (SD 11.3) at baseline to 22.1 (SD 11.2) at 6 months and 21.6 (SD 11.3) at 12 months. The emotional dimensions reduced from 11.3 (SD 7.5) at baseline to 10.9 (SD 7.5) at 6 months and 10.4 (SD 7.4) at 12 months. All of these changes were found to be significant at the 0.05 level.
Quality of Life – SF12

Quality of life was measured using an established valid and reliable instrument. The SF12 allows the individual to rate how they perceive their physical and mental health. The instrument provides a score between 0 and 100 where 0 indicates a very poor perception of their own health and 100 a very good perception.

Perceptions of physical health were very poor for this population prior to entering the study, a mean of 28.0 (SD 7.7) compared with a population mean of 50.0 (SD 10.0), but improvements were observed at 6 months and 12 months, 28.6 (SD 7.4) and 29.3 (SD 7.3) respectively, Figure 3.

Mental health was rated better than physical health at baseline 45.8 (SD 12.6) it was still below the average for the population. Improvements were observed at both 6 and 12 months, 47.1 (SD 12.4) and 47.0 (SD 12.5) respectively, Figure 4.

Figure 3: Physical components of the SF12 at baseline, 6 and 12 months.
**Hospital Anxiety and Depression Scale**

In order to understand the relationship between an individual’s heart failure and their emotional health we used an instrument to measure the changes in anxiety and depression between starting the study and 6 and 12 months after starting the study. The Hospital Anxiety and Depression Scale measures anxiety and depression whereby higher scores indicate increased depression and anxiety.

Over the course of the study we observed small changes in levels of anxiety experienced by the patients and a small, but not clinically significant, increase in depression.

**Patient Satisfaction**

We measured how satisfied a patient was with their care from the heart failure nurse at 6 and 12 months after starting the study. We measured satisfaction across 4 major areas: general satisfaction with the care received, professional care received by the heart failure nurse, the depth of the relationship between the patient and the heart failure nurse and how much time the patient felt the heart failure nurse spent on them as an individual. All of these dimensions decreased between 6 and 12 months indicating the patients became less satisfied by the care they received. General satisfaction from 78.8 (SD 14.9) to 76.4 (SD 14.9), professional care from 82.6 (SD 14.1) to 79.7 (SD 16.2), depth of relationship from 78.1 (SD 17.6) to 76.6 (17.9) and perceived time from 62.1 (SD 24.0) to 61.1 (SD 23.7).
<table>
<thead>
<tr>
<th></th>
<th>Baseline (n= 954)</th>
<th>Month 6 (n = 801)</th>
<th>Month 12 (n=729)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean diff (SE)</td>
</tr>
<tr>
<td><strong>Self-care behaviour</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12 – 60; 0 = better self care)</td>
<td>21.2 (8.0)</td>
<td>23.2 (7.7)</td>
<td>0.98 (0.25)**</td>
</tr>
<tr>
<td><strong>Minnesota Living with Heart</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Failure (0–105; 0 = Fewer problems)</td>
<td>48.8 (24.4)</td>
<td>45.9 (24.3)</td>
<td>-2.84 (0.68)**</td>
</tr>
<tr>
<td><strong>Overall score</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>23.2 (11.3)</td>
<td>22.1 (11.2)</td>
<td>-1.12 (0.33)**</td>
</tr>
<tr>
<td><strong>Emotional Dimensions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11.3 (7.5)</td>
<td>10.9 (7.5)</td>
<td>-0.39 (0.22)</td>
</tr>
<tr>
<td><strong>SF12 Quality of Life</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0 – 100; 0 – Poor, 50 population mean)</td>
<td>28.0 (7.7)</td>
<td>28.6 (7.4)</td>
<td>0.6 (0.25)*</td>
</tr>
<tr>
<td><strong>Physical health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>45.8 (12.6)</td>
<td>47.1 (12.4)</td>
<td>1.3 (0.38)**</td>
</tr>
<tr>
<td><strong>Mental health</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9.0 (1.6)</td>
<td>9.0 (1.6)</td>
<td>0.02 (0.07)</td>
</tr>
<tr>
<td><strong>Hospital Anxiety &amp; Depression</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0-21; 0 low)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>83.7</td>
<td>83.5</td>
<td>84.8</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>62.8</td>
<td>64.0</td>
<td>66.4*</td>
</tr>
<tr>
<td><strong>Borderline cases (HAD &gt; 8) %</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>14.1</td>
<td>14.9</td>
<td>15.4**</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>5.3</td>
<td>5.3</td>
<td>7.8**</td>
</tr>
<tr>
<td><strong>Confirmed cases (HAD &gt; 11) %</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>14.1</td>
<td>14.9</td>
<td>15.4**</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>5.3</td>
<td>5.3</td>
<td>7.8**</td>
</tr>
<tr>
<td><strong>Satisfaction with service</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(0-100) 100 – Total satisfaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>General satisfaction</strong></td>
<td>78.8 (14.9)</td>
<td>76.4 (14.9)</td>
<td>-2.4 (0.47)**</td>
</tr>
<tr>
<td><strong>Professional Care</strong></td>
<td>82.6 (14.1)</td>
<td>79.7 (16.2)</td>
<td>-2.9 (0.55)</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>78.1 (17.6)</td>
<td>76.6 (17.9)</td>
<td>-1.5 (0.64)*</td>
</tr>
<tr>
<td><strong>Perceived Time</strong></td>
<td>62.1 (24.0)</td>
<td>61.1 (23.7)</td>
<td>-1.0 (0.94)</td>
</tr>
</tbody>
</table>

* significant at the 0.05 level
** significant at the 0.01 level

Table 4: Survey patient outcomes at baseline, month 6 and 12 months.
4.3 Health related Quality of Life and satisfaction with care: Carer Survey

As well as investigating changes in the way patients perceived their overall health and satisfaction with care received from the heart failure nurse, we also asked patient carers to answer a series of questionnaires at the start of treatment and 6 and 12 months after the start of treatment.

Description of the carer sample

A total of 342 carers consented to take part in the survey. Average age was 65.8 years. 88% of carers were spouses of the patients, 9% children, 1% siblings and 2% friends or other relatives.

Analysis of survey responses for carers at baseline, month 6 and month 12.

Overall results of the analysis are reported in table 6.

Quality of Life - SF12

We measured both physical and mental aspects of health related quality of life using the SF12. In terms of physical health, carers reported a small decrease in physical health over the course of the survey period from baseline, mean 39.4 (SD 7.1), to 6 months, mean 38.8 (SD 6.7) to 12 months, mean 38.5 (SD 6.7), Figure 5.

Mental health on the other hand saw a slight increase from 45.5 (SD 11.8) at baseline to 46.6 (SD 11.6) at 6 months and 46.3 (SD 11.8) at 12 months, Figure 6.
Care giving Demands Scale

We used an instrument specifically designed to assess the demands on carers across three domains. The physical demands of caring, the impact caring had upon the carer’s perceived role and financial demands of caring. Physical demands of caring decreased from 21.2 (SD 21.5) at baseline, 19.6 (SD 14.1) at 6 months and 19.0 (SD 20.6) at 12 months. Role alteration also slightly decreased at 6 and 12 months as did the financial aspects of caring.

Carer Satisfaction

We measured how satisfied a carer was about the care the patient received from the heart failure nurse at 6 and 12 months after starting the study. We measured satisfaction across 4 major areas; general satisfaction with the care received, professional care received by the heart failure nurse, the depth of the relationship between the patient and the heart failure nurse and how much time the patient felt the heart failure nurse spent on them as an individual. General satisfaction, professional care and perceived time saw small but not significant decreases over time whereas depth of relationship increased by a small but not significant amount. General satisfaction decreased from 79.2 (SD 16.6) to 77.6 (SD 16.6). Professional care decreased from 78.7 (SD 14.8) to 78.4 (SD 15.8). Depth of relationship increased from 72.1 (SD 17.6) to 72.9 (18.6). Perceived time decreased from 61.6 (SD 21.4) to 60.3 (SD 21.9).
Summary: Key Findings and Interpretation

- The survey aimed to see if nurses had an impact on patient and carer HRQoL and satisfaction with care. Patients also completed a self-care behaviours scale, whilst carers completed a care giving demands scale.

- A large number of patients and carers participated, completing the questionnaires at first contact with the nurse, and again after six and 12 months. This was only a small proportion of the nurses’ caseload. Comparison showed that those who completed the questionnaires were representative of the whole caseload, apart from having more contacts with the nurse, and fewer co-morbidities. This may be due to nurses recruiting more people who were the newly diagnosed with fewer co-morbidities, and spending time up titrating their medications resulting in more contacts.

- The health-related quality of life measures showed a significant improvement over the year. This is an impressive finding as due to the progressive nature of heart failure, many patients’ quality of life deteriorates over that amount of time. We used the MLHF to find out how their heart failure impacted on their physical and mental health, and the SF12 to measure their general perceptions of their health. The MLHF scores improved significantly, meaning that their heart failure was having less impact at six and 12 months than it had on their activities.
of daily living at baseline. At 12 months, patients who had fewer co morbidities had the highest improvement in score. Also the more breathless patients (according to their New York Heart Association class) showed less improvement in their ability to perform physical daily activities. Measuring HRQOL with the SF12 showed that whereas patients’ physical health is poorer than the health of the general population, their emotional well being is similar.

• Patients had good levels of self-care behaviours knowledge the first time they filled in the questionnaire, which decreased slightly over the year. This may be because the first time they completed the form was shortly after their first meeting with their HFSN, during which she will most likely have provided them with education about living with heart failure and how to manage it. However, this finding does underline the importance of regularly reminding patients of how to look after themselves.

• The HADS measures anxiety and depression. It is scored to show if someone is borderline or definite (confirmed) in terms of having anxiety or depression needing treatment. According to the HADS, almost all patients were borderline or confirmed cases of anxiety. By the end of the year a significantly higher proportion had confirmed anxiety. Whilst there were more people who were below the threshold for borderline depression, over the year the proportions showing borderline or confirmed depression increased significantly. Although these changes are significant statistically, they may not be in a clinical sense. However, it is clear that the nurses were not able to improve the anxiety and depression of their patients. It is therefore important that they regularly assess the mental health of their patients to see if they need a referral to psychology services, if available, or their GP.

• As measured by the SF12, carers had better physical health than the person they cared for, but it actually got worse over the year, and is poor compared to the general population. This may just be due to ageing, or possibly due to having to do more of the physical tasks such as gardening, shopping and cleaning that the heart failure patient can no longer do. However in the care giving demands scale, carers did not report that they had high difficulty in helping with the care of the patient. This will be discussed more in Chapter 7.

• Patients and carers were very satisfied with the care they were receiving from the nurses, but this decreased slightly over time. This may be due to the fact that most patients saw the nurse an average of seven times. This may well have been in the first part of the year and then they were discharged from the service.
Chapter 5

Service impact on hospital admissions and cost benefits

5.1 PCT, HES and Audit data

Each PCT was contacted in August 2005 and asked to provide retrospective data on all heart failure admissions and re-admissions in the year prior to heart failure nurses taking up post. Only 35% of PCTs were able or willing to provide the required data. To address this problem we have sourced both retrospective and prospective heart failure admission data and all cause admission data across all PCTs in England from the National Hospital Episode Statistics database.

All of the specialist nurses, apart from one site, are using the Athena database to collect information about their patients and part of this information has been sent to York in an anonymous format. All centres apart from two have transferred data. We now have data for 9,354 patients.

5.2 Economic Analysis

Establishing whether the use of heart failure specialist nurses benefit heart failure patients is only one aspect of the overall evaluation process. Decision makers have to consider the relative costs of providing heart failure specialist nurses and establish whether these costs benefit the overall use of National Health Service resources. In order to assess this aspect of the project we need to assess both the overall costs of providing the heart failure specialist nurse service and then compare this with the potential cost savings the heart failure nurse service brings to the NHS.

As part of this process we need to consider who will bear the costs of the service and for this part we take a narrow perspective and include only those costs borne by the NHS. We then consider the total nurse associated costs including salaries, overheads, management costs and the cost of training and supervision. This cost is £35,000 per nurse per annum. In order to assess the costs of patients we use the costs associated with readmissions and use a standard reference cost to calculate a total cost for all patients. The reference cost is the Department of Health Payment by Results E19 tariff cost of £2,101 per patient admission.

In order to assess the costs associated with the heart failure nurse service we derive, from the Athena data set, the number of patients seen in each PCT by heart failure nurses, and the total number of readmissions for these patients over a 12 month period (April 2005 – March 2006). We then need to compare this with the total number of patients in the PCT over the same period not seen by a heart failure nurse and their related admissions over the same period. Unfortunately the form the HES data takes only provides aggregate data for the patients not seen by a heart failure nurse, rather than individual data that we have for patients seen by a HFSN. So in order to estimate the potential savings we utilise a modelling technique to estimate the potential costs associated with heart failure patients in each PCT in the absence of the heart failure service. We then compare the actual costs borne by the PCT in the accounting period with the estimated costs. This provides an indication of the saving due to the heart failure specialist nurse service.

In order to test the stability of the model derived we compared our estimated readmission rates per heart failure patient in each PCT with the
observed readmission rates in a 12 month period prior to the introduction of the heart failure nurse service. These comparisons were very similar and provided some confidence that the model derived was appropriate.

5.3 Results

Overall the heart failure specialist nurses saw 4,409 patients over a 12 month period compared with 13,049 patients discharged with a diagnosis of heart failure over the same period, a total of 34% of all heart failure patients.

Our first analysis estimates the difference in probability of being readmitted if a patient was seen by a heart failure nurse compared with not being seen by a heart failure nurse. For those seen by a heart failure nurse the number of readmissions, on average was 0.18, for those not seen by a heart failure nurse the average was 0.97 (Figure A).

Those patients seen by heart failure nurses were far less likely to be readmitted than the overall population. Our analysis indicates that this result is statistically significant and is unlikely to have occurred by chance and is due to the heart failure nurse service.

The next stage is to establish whether, for those patients who are readmitted, there is a difference in the duration of their readmission. We compared the average duration as an inpatient for heart failure nurse patients readmitted compared with all patient diagnosed with heart failure over the same period. The patients seen by the heart failure specialist nurses who were readmitted spent a longer period as an inpatient than the population diagnosed with heart failure (11.6 nights versus 8.6 nights, Figure B).

Figure A: The probability of readmission for heart failure nurse patients compared with all patients diagnosed with heart failure.
These results indicate that the patients seen by heart failure nurses are admitted less often than the general heart failure population, but when they are admitted it is for a longer period of time on average.

One of the key questions we need to address in this project is what impact the heart failure specialist nurse service had upon all cause readmission rates when compared to a 12 month period prior to the introduction. In order to assess this we compared the readmission rate in a 12 month period when heart failure nurses were in post, April 2005 to March 2006, with a 12 month period prior to them being in post. In the year prior to their introduction the rate of readmission of heart failure patients was 1.31 and in the year after their introduction the rate was 0.97, this is equivalent to a reduction in readmissions of 35%. One question which arises from this is whether this reduction would have occurred anyway in the absence of heart failure nurses being in post, as with most observational studies employing historical controls it is possible that other changes in the environment lead to changes observed rather than the introduction of heart failure nurses. In order to address this question we used our modelled data to estimate what the readmission rate would be in the absence of heart failure nurses. Our data suggested that this readmission rate was 1.34, similar to historical control period. We can be confident in attributing the reduction in readmissions to the introduction of heart failure nurses.

The next stage of the analysis involves estimating the costs associated with the introduction of heart failure nurses and countering these costs against the potential cost savings from the heart failure nursing service. We estimated that the total cost of an individual heart failure nurse was £35,000. This cost is generated from the British Heart Foundation actual costs. This figure includes the cost of the nurse salary, any overheads, a management cost and the cost of training. The total cost of all of the heart failure nurses over a 12 month period was £420,000. In order to calculate the cost savings, we estimated the potential cost savings from the reduction in readmissions. We estimated that the potential cost savings from the reduction in readmissions was £200,000. This figure is based on the estimated cost of readmissions and the reduction in readmissions. Therefore, the net cost of the heart failure nurse service was £220,000, which is £220,000 less than the potential cost savings from the reduction in readmissions.

Figure B: The average time spent as an inpatient for each admission for heart failure nurse patients compared with all patients diagnosed with heart failure.
period was £2,439,500. We then calculated the actual costs of readmissions in the period in all PCTs by taking the recorded number of readmissions, 12,644 for 13,049 patients diagnosed with heart failure in the period, and multiplying this by the cost of an admission, derived from the Department of Health payment by results cost of £2,101 per patient admission. This provided an estimate of the total cost of readmissions over the period of £26,565,044. Using our modelled data we then estimated, using the same reference cost, the cost of all readmissions if the heart failure nurses had not been in post and derived an estimate of £37,576,350. This means that the saving due to the heart failure nurses was £11,011,306. From this figure we deducted the actual cost of the heart failure nurses and derived a figure of £8,571,806. By dividing this figure by the number of patients diagnosed with heart failure in the period, we can estimate that the money saved through a reduction in readmissions by the heart failure nursing service is the equivalent of £657 for each patient diagnosed with heart failure across the entire PCT, this figure is over and above the costs of the heart failure nurses.

As the heart failure specialist nurses only saw 34% of those diagnosed with heart failure in the period, we then estimated what potential savings those patients seen by the heart failure nurses had over all patients diagnosed with heart failure. In order to assess this we estimated the actual cost, in terms of readmissions, for a patient diagnosed with heart failure and compared this with the actual cost of those seen by heart failure nurses. The results indicate that each patient seen by a heart failure nurse costs on average £1,944 less than patients diagnosed with heart failure but not seen by a heart failure nurse, this figure is over and above the costs of providing the heart failure nurse service.

One issue that arises from this analysis involves the variation across PCTs. Some heart failure specialist nurses saw a greater proportion of patients than others. Figure C plots the savings per patient seen by the heart failure specialist nurse across all of the PCTs involved in the study.

Figure C: Mean Cost savings in £’s for each patient seen by heart failure specialist nurses across all PCT’s.
We can see that there is a large variation in the cost savings for heart failure patients across the PCT clusters, from an increase in cost of £2,712 per patient to a cost saving of £7,361 per patient. In order to provide an accurate estimate of the potential savings across PCTs we calculate the median value and the inter quartile range. The median value is £1,826, range £1,041 to £2,610. Taking this figure we can suggest that the patients seen by heart failure nurses cost £1,826 per patient less than patients not seen by heart failure nurses over the 12 month period in respect of readmissions. This figure is over and above the costs associated with the nurses. The heart failure specialist nurses saved the PCTs they were employed in excess of £8 million over the 12 month period.

Summary

• Heart failure nurses saw 34% of all patients discharged from hospital with a diagnosis of heart failure in the 12 month period.
• The number of all cause readmissions during this period was 35% less than in the 12 months prior to the nurses coming into post.
• Patients seen by heart failure specialist nurses were less likely to be readmitted, but when they were they tended to be admitted for a longer duration (11.6 nights compared to 8.6 nights before the nurses were in post).
• Heart failure specialist nurses have the potential to save significant sums of monies through reductions in readmissions; this is estimated as £1,826 per patient seen over and above the cost of the heart failure nurse.
Chapter 6

The eight questions: key points and conclusions

1. Did the new services improve patient access to specialist heart failure care?

Overview

All centres have successfully developed their services, and although there are different models of service in each locality, all nurses have full caseloads. Most patients are referred from secondary care, from cardiology wards and clinics, general medical wards and medical admissions, and, much less frequently, from care of the elderly wards. Most nurses aim to carry out at least one home visit, and then will see patients again at home or in a nurse led community and/or secondary care clinic. More patients get seen when nurses run clinics, but home visits are still needed for people with less mobility to enable equal access to the nurses. Referrals also come from Primary Care but care has to be taken that these are appropriate and useful to the patient.

Many nurses are implementing palliative care groups and support groups, cardiac rehabilitation and exercise groups, and several have recently passed their nurse-prescribing course, enabling them to provide a better service to patients. As the service has developed, many nurses report a tension between ever increasing caseloads and these other activities. An ideal “active” caseload is seen to be 50-60 patients, with the remainder of the caseload “inactive” and being managed and monitored by other community staff. There is a need for a discharge policy in order to avoid an ad hoc and inconsistent approach.

Key findings

- The 76 nurses see approximately 5,000 new patients a year. Most have an active caseload of over 60 patients each. Caseloads are increasing as more clinicians refer in to the service. In general, nurses see approximately 34% of all people with heart failure in the PCT, thus they report knowing they are only ‘scratching the surface’. However, this compares well with the rest of the UK where 20-24% of patients receive specialist heart failure follow up.
  - Most referrals still come from cardiology but increasingly from other secondary care wards and GPs. This can lead to inequity of access for those patients not under the care of a cardiologist.
  - Inequity of access to the HFSN service is created by geographical boundaries with lack of HFSN service provision in neighbouring PCTs.
  - There is a tension between seeing as many patients as possible (clinics) with the needs of patients who need home visits. However, all patients should have at least one long home visit post discharge from any ward to enable increased understanding of their condition and how to manage it.
  - Most nurses operate some kind of discharge policy. In general nurses tend to discharge stable optimised patients to primary care. If this is to work well, good links are needed with the primary care team, including community matrons. These staff need to be confident in managing stable heart failure patients, but call in HFSNs as necessary. Those patients with advanced heart failure tend to be kept in the active caseload and palliative care brought in to help with their management when appropriate.
  - Nurses are the key workers for their patients, supporting other professionals using a multidisciplinary approach to managing heart failure across acute and community settings (see Model 1 with appendices).
• Nurses are now implementing innovative new schemes to improve patient care and access to services needed. Examples of these include; day therapy in hospice, support groups, 1 stop heart failure clinics, cardiac rehabilitation, intravenous therapy in the community, early discharge support, and using heart failure health care/support assistants for collecting bloods and checking on patients.

Conclusions

Nurses as key workers are having a significant impact on quality of life for patients, who are receiving better access to other services and much needed continuity of care. Although based in primary care, nurses need strong links with cardiology and other staff in secondary care who can ensure referrals are made from all wards.

Recommendations

• This study shows that currently, most patients are referred from cardiology wards. This disadvantages the majority of patients who aren’t under the care of cardiology. Every service should develop a referral pathway to ensure that these patients are not excluded.
• All services should adopt an individualised approach to assessment and intervention.
• All patients should have the opportunity to access clinic or home based care.

2. Did the service extend healthcare teams’ methods of managing heart failure?

Overview

In their quarterly monitoring reports, and at interview in the case study sites, nurses report having taught many staff to manage stable heart failure patients. Some nurses are not only teaching district nurses, community matrons and others in primary care, but also teach on post-registration modules for nurses at local universities.

Key findings

• Where there are good links with the primary care team, the nurses have been able to extend knowledge of how to manage stable optimised patients, but retain links to ensure they will be contacted by either the patient or his primary care team should there be a problem.
• Many clinicians and managers acknowledge the special contribution of the heart failure specialist nurses as ‘adding value’ to services.
• The key message from medical colleagues was that rather than fitting into existing multi-disciplinary teams in primary care, the HFSNs were the main link between different professionals from primary, secondary and community care services, facilitating better communication between GPs and cardiologists, resulting in better quality of life for patients and continuity of care across sectors.
• Nurses took varying amounts of time to feel confident in their role, and need support whilst learning, as do junior doctors. They now feel they have enough expertise to carry out their role effectively and share their knowledge across the primary care team.
• It appears that in most areas, the HFSNs have managed to develop a model of holistic care that is patient focused and yet sustainable in the long run.
• There was some evidence that where the management of patients was passed on to the primary care team, patients were not always referred back to the HFSN when they started to deteriorate, leading to unnecessary readmissions.

Conclusions

As heart failure nurses are a limited resource, they have to manage their caseloads to ensure they see those most in need of their skills. They can do so by involving other professionals such as heart failure support nurses, or healthcare assistants in the more routine checks.
Once stable, patients can be managed in primary care but should be referred back to the care of the HFSN if their condition deteriorates.

**Recommendation**

Nurses must be seen as the key worker across settings in order to improve communication and patient management. The skills of the HFSN are best utilised when the service has a broad skill mix, including health care assistants.

### 3. How should services be organised?

**Overview**

As with all new services, trust has been gained slowly from some professionals in both primary and secondary care. Having a GP, cardiologist or geriatrician with an interest in heart failure acting as a champion for the service, helps considerably.

It has been a challenge to develop a new service within an increasingly complex and fluid healthcare system. The new models of commissioning services and PCT reorganisation have had some negative impacts on the development of the role. For example, there may be conflict between the roles of Community Matrons and HFSNs.

**Key findings**

- Cardiologist and medical support is crucial to the development of the HFSN service caseload and to promote equity of access to the service by all people with heart failure.
- Links into the multidisciplinary team (MDT) vary by locality, with some having more success than others. This can be influenced by the way the nurse is perceived and where she is located. For example, the term specialist nurse can lead to a perception of her belonging to secondary care, even though based in the community. The background and experience of the nurse also influenced the speed at which links were made with the MDT.
- Nurses are able to work across the primary/secondary care divide. There have been pressures of legitimising a new role and competencies across a vertical and horizontal hierarchy.
- The existing systems of care vary from area to area. There may be some overlap with community matrons in some areas, so joint working needs to be encouraged.
- Although some GPs were slow to accept HFSNs, they are now seen as valuable assets to the primary care team. There are still some GPs with anxieties about HFSNs prescribing.
- Nurses up titrating and monitoring medications are a valuable tool for both GPs and cardiologists, and can help GPs meet their QOF targets for this patient group.

**Conclusions**

There are significant benefits to having heart failure nurses based in the community and ‘owned’ by the PCT. Care needs to be taken to ensure these posts are seen as part of the community team. Being based in the community gives much better access to the MDT. There are some drawbacks, in particular, referral pathways appear to largely favour those being discharged from cardiology wards. There is some evidence of an unhelpful lack of joint working between chronic disease management teams and specialist nurses.

**Recommendation**

Heart failure specialist nurses should be included in the management of the HF patient by the MDT.

### 4. Did the service meet the needs of the South Asian patients?

**Overview**

Since people without English as their first language were likely to be excluded, by default, from completing health related quality of life
(HRQoL) and satisfaction with care measures, a sample of patients and carers of South Asian origin were interviewed to gain their views of the service and whether it is improving their HRQoL. We did not find any ‘essential’ (overriding) cultural or religious features in any of the South Asian groups that we could identify as underpinning their experience of heart failure and the HFSN service. We found three main ‘scenarios’ resulting in qualitatively different levels of access to HFSN services. These varied from excellent medical and psycho-social support in one site, to another where support focused largely on medical issues and drug titration, and in one extreme case, to minimal medical support and no direct involvement of a HFSN.

Key findings

- In general, the needs and experiences related to heart failure, and the benefits of the HFSN service, are similar for the minority ethnic participants and white participants who took part in the larger survey.
- More than gender, it seems, the socio-economic background and ‘social capital’ (i.e. access to English and alternate sources of information) mark internal differences within each ethnic group.
- In general, most people found the nurses very helpful in understanding their condition, optimising their medication, and getting speedy access to services they needed. Participants felt reassured by the fact that they could contact the nurse whenever they needed and s/he had time to listen to their problems and point them in the right direction.
- It appeared that, at times, assumptions were made by some professionals. For example, South Asian patients couldn’t speak English and/or would not avail the specialist heart failure nursing service due to ‘cultural issues’, and hence were not offered the services that were available to the white patients.
- In one particular area, all of the patients interviewed, except one, had no direct contact with a heart failure specialist nurse until recently, even for titration of medications and even though three of them spoke English. They were seen by a bilingual cardiac community nurse who provided them basic information and contact with the service based in the hospital, providing little sense of continuity or psycho-social support, resulting in patients feeling neglected and discriminated against.
- Equally importantly, we found examples of good practice suggesting that it is possible to provide an equitable service to people of ethnic minority backgrounds, given the commitment of nurses and leadership within local teams.

Conclusions

It is possible to provide an equitable service to people of ethnic minority backgrounds without pre-defining their needs as special or different. At the same time, one of the important findings from this work suggests that even where the resources are available, stereotypical assumptions about ethnicity and difference can structure services to exclude patients and carers who are from minority ethnic groups in a manner that leads to neglect and feelings of discrimination.

Recommendations

- More attention should be paid to training NHS staff to help them understand and engage with issues of providing services for people of different ethnic and socio-economic backgrounds.
- Training must incorporate sharing models of good practice and challenging assumptions about minority ethnic groups as homogenous communities whose needs and experiences are predefined by religious and cultural norms.
- Care should be taken to monitor the quality of services provided to minority ethnic and other marginalised groups, to ensure equity of services as envisaged in the NSF.
5. Did the service affect the patients’ health related quality of life? How satisfied were they with the service?

**Overview**

Overall, the nurses appear to have had a significant positive impact on health related quality of life, and patients and carers are highly satisfied with the care they provide.

**Key Findings**

- 10% of patients seen by nurses completed our survey, but the sample of 954 patients and 342 carers exceeded our target. The demographics were similar to those patients who did not complete the survey, but when compared to those non-participants nurses gave us details for (297), non-participants were more likely to be older, male and NYHA IV. Survey patients were also more likely to have had more contacts with the nurses and have fewer co-morbidities.

- Looking at other studies using the Minnesota Living with Heart Failure (MLHF) questionnaire, which measures the impact of heart failure on daily living, our study patients had much higher baseline scores, showing worse levels of health related quality of life. There was significant improvement from baseline at 6 months and 12 months in both the disease specific (MLHF) and generic HRQoL measure (SF 12) used.

- Self-care scores were good at baseline and did not improve overall. It would appear that there were improvements in uptake of flu jab and increased exercise, but a slight decrease in the score on other items in the questionnaire.

- Anxiety and depression scores did not improve.

- Patients were highly satisfied with the care from the HFSN. But over the 12 month follow up satisfaction decreased slightly. This may be linked to discharge from the service.

**Conclusions**

There was significant improvement in patients’ health related quality of life over a one year follow up period and patients were very satisfied with the care they received. An important role of HFSN services is to provide education and support to patients and their carers about the condition and its management, which may need to be done more regularly to maintain high levels of self care behaviours.

**Recommendation**

Anxiety and depression should be routinely assessed using recognised standardised measures. When appropriate, patients should be referred to their GP for onward referral to psychology services or medication.

6. How does the caring role impact on family carers, and is this role and their quality of life affected by the new service?

**Overview**

The majority of carers are spouses and female. Carer age is about six years younger than the patients’ age. As we know, caring can be exhausting for some carers. We assessed the physical demands of caring, the impact caring had on the carer’s perceived role and the financial demands of caring. We also assessed general health-related quality of life and satisfaction with the care provided by the HFSN service.

**Key findings**

- Carers’ physical health score at baseline was better than that of the patients but poor compared with population norms, and the score did get worse over the year (Figure 2).

- Carers SF12 mental health component score was similar to that of the person they were caring for.
• Although improved at 12 months, physical aspects of care giving are more difficult than for patients with other chronic conditions.
• Role alteration and financial aspects of care giving are similar to carers for patients with other chronic conditions.
• Physical demands of caring, role alteration and financial alteration are associated with worse mental health components of quality of life.

Conclusions
Carers may have poor physical health which is getting worse over time. They appear to have found the HFSN service helpful in relieving some of the aspects of care giving.

Recommendations
Carers’ needs should be regularly assessed to see if they have adequate support and respite to enable them to carry out their role.

7. Did the service reduce all cause admissions to hospital?

Overview
By comparing Hospital Episode Statistics over a one-year period on all cause admissions for patients with a diagnosis of heart failure with nurses’ data on their patients all cause admissions in the same period, we have been able to model the difference in admission rates between patients with or without a HFSN.

We also compared the admission rates in the same 12 month period when heart failure nurses were in post, with a 12 month period prior to them being in post.

Key findings
• Heart failure nurses saw 34% of all patients diagnosed with heart failure in the 12 month period.
• For those patients seen by a heart failure nurse, the number of readmissions, on average, was 18 per 100. For those patients not seen by a heart failure nurse, the average was 97 per 100. Patients seen by heart failure nurses were far less likely to be readmitted than the overall heart failure population. Our analysis indicates that this result is statistically significant and is unlikely to have occurred by chance and is due to the heart failure nurse service.
• Patients seen by heart failure specialist nurses were less likely to be readmitted, but when they were they tended to be admitted for a longer duration (11.6 nights compared to 8.6 nights before the nurses were in post). This may reflect the fact that admissions were for more serious events with minor events being managed by the nurse outside hospital.
• Nurses reported that they were aiming to reduce inappropriate emergency admissions but may plan necessary admissions.
• Nurses suggest that fewer unnecessary admissions are due to the close monitoring to avoid blood urea and potassium imbalance; medication changes including diuretics, and close liaison with other members of the MDT.
• Heart failure specialist nurses have the potential to save significant sums of monies through reductions in readmissions; this is estimated as £1,826 per patient seen over and above the cost of the heart failure nurse.

Conclusions
Nurses had a significant impact on all cause admissions to hospital for their heart failure patients. Patients are less likely to have unplanned admissions, but once admitted may stay in longer. This is similar to the national average, (12.7 nights) and may reflect the planned nature of the intervention or local policies rather than the patient needing to be there.

Recommendations
All heart failure patients should have a heart failure specialist nurse as part of their management team.
8. What was the impact of the service on healthcare costs?

Overview
Establishing whether the use of heart failure specialist nurses benefit heart failure patients is only one aspect of the overall evaluation process. Decision makers have to consider the relative costs of providing heart failure specialist nurses, and establish whether these costs benefit the overall use of National Health Service resources. In order to assess this aspect of the project we assessed both the overall costs of providing the HFSN service, and then compared this with the potential cost savings the heart failure nurse service brings to the NHS.

Key findings
• The total cost of a nurse including, salary, overheads, management and training costs was £35,000 per year at the time of analysis.
• Economic modelling of PCT level HES data showed that patients who were able to see a HSFN had a median cost saving of £1,826 compared to patients from the same PCT diagnosed with heart failure but not seen by a HFSN. This figure is over and above the costs of providing the HFSN service. The median is used to obtain an average where there is a large variation in costs.

Conclusion
Heart failure specialist nurses may have the potential to save significant sums of money through reductions in admissions. HSFN nurses in this project were associated with a total saving to the NHS of £8,050,834 over the year sampled.

Recommendation
As HFSNs have a potentially significant impact on reducing healthcare costs for the heart failure patients they see, it would seem sensible to ensure that a greater proportion of heart failure patients than the current 34% are seen by a HFSN.
Chapter 7

Discussion

7.1 Introduction

The answers to each of the questions we asked, and the recommendations that follow, appear in the previous 6 chapters. In this chapter we begin by outlining the main strengths and weaknesses of the methods used. We then address some more specific questions about the methods and measures we used. Finally we discuss why some of the findings were contrary to those we expected.

There is already evidence to suggest that HFSNs impact positively on patient care in a cost effective manner, reducing hospital admissions and improving quality of life.1,30,31 However most of these studies were randomised controlled trials (RCTs) from countries other than England, and the nurses were usually based in hospitals.

7.2 Strengths and Limitations of the study

7.2.1 General Methodology

The strength of this pragmatic research study is that we assessed the impact of HFSNs placed in English PCTs, working with ‘real life’ caseloads, and we explored the barriers and facilitators of implementing this new, primary care based service. In complex interventions, such as this, where nurses are working as part of multidisciplinary teams in a wide variety of locations, a complex evaluation using a mixed methods approach is highly appropriate. Therefore, our evaluation incorporated both quantitative and qualitative methods to provide rich in-depth data and explored how the benefits accrued. However, as the study was not a randomised controlled trial it is not possible to infer that all of the outcomes we observed were due solely to the presence of the nurses.

7.2.2 The case study interviews with nurses and multidisciplinary teams

Interviews with HFSNs and members of the MDT provided a detailed picture of what HFSNs do and how they might impact on patient access to the heart failure specialist care and management. To frame the study a theoretical model proposed by Aday et al (2003) was used to gain understanding of perceived access to the HFSN service. Seven case studies were examined using purposive sampling. The aim of sampling was to explore development of the HFSN service in a variety of settings to represent the diversity of service developments supported by the BHF (See Appendix 6).

Findings generated rely on self-report data, though a potential weakness is these data may be biased by the nurses’ desire to promote their service. However, the interviews with the other health professionals who interacted with the nurses provided a degree of triangulation and confirmed the nurses’ reports.

7.2.3 Assessing HRQoL and satisfaction with care

A strength of the design was that data management staff of the York Trials unit collected, managed and analysed the data independent of the main researchers.
They achieved good recruitment and follow up rate, exceeding the numbers that were needed to show a statistically significant difference (using a power calculation).

A potential weakness was that only 10% of the patients completed questionnaires and that recruitment rates varied very widely between nurses, something we had no control over. We compared the demographic and medical data of those who did and did not complete the HRQoL questionnaires. In all but two aspects there was no significant difference. The exceptions were that the patients taking part in the survey had fewer co morbidities and had a higher number of contacts with the nurse. Examining the data suggests that this was because the nurses were less likely to give the questionnaires to the very ill patients, feeling that this was asking too much of the patient and more likely to ask the newly diagnosed patients. The reason for the greater number of contacts being that they spent more time with these patients up titrating their medications.

**Quality of life measures**

We utilised widely used well validated measures, both disease specific and generic to assess the impact of heart failure and co morbidities on quality of life. The fact that only 10% of the caseload completed these has been noted above. A literature review of other studies using the MLHF and the EHFSbCS showed that our sample had poorer HRQOL according to the MLHF (mean overall score 48 vs. range 25-44) showing that the patients seen by the community based nurses had poorer physical function, mental health and well being than those studied in previous research.

**Patients’ knowledge of self management**

The European Self-care Behaviours in Heart Failure Scale measures how much patients know about the self-management of heart failure. Our patients had lower self care behaviour scores at baseline than other study populations, indicating high levels of self care (21 vs. range 24 – 33). Unfortunately, we suspect that the majority of nurses provided their patients with education about living with heart failure and how to manage it during their first visit, and then invited the patients to participate in the research and gave them the questionnaire. Thus most patients would recently have had a self-management intervention shortly before completing the measure, explaining the good baseline score.

**Anxiety and depression**

We used the HADS to measure psychological status. The items measuring anxiety seem to be valid and reliable, however the items measuring depression may be less valid in people with heart failure. Two of the items ask about feeling slowed down and whether you still enjoy the things you used to enjoy. A number of patients indicated through writing on the questionnaire that they were answering yes because of restrictions imposed by symptoms, not because they were depressed. Thus the score shown for depression may in some cases be inflated and in future studies it may be better to seek an alternative measure of depression.

**Satisfaction with care**

The satisfaction with care questionnaire was developed for use in primary care. It has been shown to be reliable, have good validity and be acceptable for use with patients under the care of GPs or community nurses. Satisfaction has been linked to health outcomes, as stressed or frustrated patients may not fully respond to therapeutic interventions. The majority of patients showed high levels of satisfaction with the care they received.

**Care giving demands scale**

It is known that acting as care giver to an individual with whom the carer has a personal relationship may have an adverse effect on the carer’s health and wellbeing. We piloted several questionnaires with our carers. The consensus
was to use the Care Giving Demands Scale to measure the impact of the caring role on carers of people with heart failure. However, on the advice of these carers and our RAG we altered the order of questions to put the more personal questions about changes in the relationship at the end.

### 7.2.4 The measures and people of South Asian origin

An unavoidable weakness of this study was that many of these questionnaires have not been translated and validated for people whose first language is not English. As we could not use these measures with patients from minority ethnic groups, we set up systems to invite patients from a South Asian background to be offered the possibility of an interview with a bilingual researcher. It became clear that this was not working because we could see on the patient database that in sites that had significant numbers of South Asian patients, few had been recruited to use either the HRQoL questionnaires or been invited to be interviewed. In response we changed our method and asked the nurses to ask these patients if a researcher who spoke their language could telephone them. This was more successful and resulted in a sample of 31 patients of whom 17 were interviewed, and 11 carers. When they were interviewed we were surprised to find that a significant number of these patients did speak (and read) English. Thus it would appear that people of South Asian origin were being excluded by default not only from the research but, as expanded on in the paragraph below, also from receiving the nursing service. It seems most likely that this is because health professionals make unwarranted assumptions about minority ethnic cultures resulting in barriers to appropriate referrals and support.

Overall it would appear that patients of South Asian origin are under-represented in this study and that there appears to be different uptake of the service in different areas of the UK. We know that the incidence and mortality from Coronary Heart Disease is higher in some people of South Asian origin. We had expected to find significant number of patients in some of the study areas. In fact only 187 of the 9354 patients in the nurses Athena database were of South Asian origin, around 2%. This was despite the fact that in applying for the nurses a number of the sites had implied that they had high proportions of minority ethnic groups who required a service. The proportion of the population of England that is South Asian is 4.2-4.6% (2001 census). One urban area has a high population of South Asians; around 16% of their population in one ward and 10.4% in another. In the BHF site in this area, where about 14% of the population are South Asian, the HFSNs had only 38 patients of South Asian origin from the total of 739 patients on their database (5%). The variation between sites can be seen by comparing this with another area, Bradford, where the overall proportion of the population that is South Asian is 19% and the nurses had 16% of their referrals from that population. We do not understand the reasons for this variation, and it may be that further research is needed to look at how these apparent inequities may be mitigated.

### 7.2.5 Assessing service impact on hospital admissions and cost benefits

A strength of the study was the pragmatic, ‘real life’ nature of the economic evaluation in a wide mixture of patients at different stages of their illness.

Although many economic evaluations use Quality Adjusted Life Years (QALYs) to show benefit, life years gained may be minimal in this patient group, many of whom are at an advanced stage in their progressive illness. The data we used was obtained from two sources. The patient management database, Athena, was where nurses recorded patient demographic and clinical information including admissions to hospital, and nursing process data such as the number of contacts by the nurse. This data was anonymised and sent to York University
for analysis. The second source was Hospital Episode Statistics (HES) data. As the majority of nurses came into post gradually over a one year period, and often had difficulty getting the database installed and running, we chose to use a time period of April 05-March 06 for our analysis comparing BHF nurses’ readmission rates with overall PCT admission rates. Ideally we would have compared data for the year before the nurse came into post with the first year they were in post. However, the slow recruitment of the nurses and the time taken to establish Athena data collection made this impossible. Another problem of using this method was that HES data is available only at PCT level, not individual patient level. This meant although we had individual patient data from the nurses, all calculations had to be done at PCT level. The accuracy of the Athena data was crucial and we were able to work closely with a few centres and check when, for example, readmission rates appeared too low. This experience meant that we were reasonably confident in the quality of our data. One qualification is that there was a wide range (10% to 80%) in the proportion of patients in the PCTs seen by the nurses. There were a number of reasons for this, such as: there only being one nurse in post, compared to other centres where a GP and Cardiologist with special interest in heart failure could refer to a team of three nurses. This variation in the proportion seen by the heart failure nurse could impact on the interpretation of the economic model in some PCTs, particularly those PCTs with high or low proportions of patients seen by the heart failure nurse. Because of this we consider the economic findings to be indicative rather than definitive. Finally it should be noted that we took a narrow perspective in our economic analysis, focussing upon costs of providing heart failure nurses and the costs of readmissions to NHS facilities. This narrow perspective fulfils the information requirements of decision makers charged with the allocation of NHS resources but it does not reflect the potential wider social and personal costs incurred by this group of patients.

7.3 Questions arising from the findings

7.3.1 What have we learned about the delivery of heart failure specialist nurses services?

The findings provided some important insights into the setting up and delivery of heart failure nurse services. This new role definitely enhanced the work of the existing team, as nurses used their specialism to mitigate patient symptoms, prevent complications, provide rapid response and slow deterioration in this progressive disease. Their advocacy skills and coordination of care improved access. Local steering group meetings should have ensured close collaboration between HFSNs and the MDT, but were sometimes not well attended.

However, the organisation of the NHS and the context of HFSN services have changed radically over the study period. This means it is very difficult to draw firm conclusions about where nurses should be based, how the service should be configured, and what competences they need to complement other members of the multi disciplinary team. It should also be noted that in general, nurses’ caseloads are not covered while they are on holiday or sick leave.

7.3.2 Did the HFSNs see a significant number of patients?

The nurses in our study saw on average 34% of those patients discharged from hospital with a coding of heart failure, and it might appear that the nurses were only ‘scratching the surface’. Nationally, only 20% of all patients discharged from hospital with a coding of heart failure had
planned specialist heart failure follow up, a recent Healthcare Commission survey of heart failure reported a similar proportion of patients (24%) as having access to specialist nurse services. We therefore feel confident that the appointment of these nurses has significantly improved access.

Those patients not being seen by the HFSNs have been discharged from hospital with a code for heart failure. Nurses report missing some patients discharged from Care of the Elderly wards and general medical wards, but also that many of the discharge codes may be inaccurate. It would also appear that now some patients are discharged to the care of community matrons, bypassing HFSNs.

There may be a number of things that could be done to improve access further. Referral arrangements could be improved, and become a standard part of discharge planning. Possibly a Heart Failure Referral Nurse or discharge nurse in secondary care would help improve access. It was very clear that most nurses were already working to capacity, so there is probably a need to appoint further nurses and to use effective systems of triage and skill mix to ensure patients are seen by the health staff appropriate to their needs, either at home, surgery or clinic. Chan et al suggest that having disease management programmes for all patients with heart failure is likely to be cost effective and result in greater aggregate health gains.

7.3.3 What was the average caseload?

Altogether, the nurses reported seeing 5151 new patients in a year, an average of 68 patients per nurse. However there were rarely 76 nurses in post at any one time, and many are part time, so the average nurse caseload of new patients is probably higher.

There is much uncertainty and debate about what comprises a ‘proper’ caseload. If nurses were seeing patients primarily in clinics (community or in secondary care) they often had a caseload of 100 or more. However, what seems to happen is that most nurses had an ‘active’ caseload of around 50-60 patients who were NYHA level III or IV. They had discharged their stable level II or III patients to the care of the GP or community nursing team, on the understanding that they would be contacted should the patient begin to deteriorate. This formed their ‘inactive’ caseload which could be 80-120 patients. It seemed that patients were discharged in a rather ad hoc way, and it might be better to have an agreed guideline or policy which could potentially reduce caseloads allowing more high risk patients to be seen.

A number of factors influenced how large a caseload a nurse could manage. Some patients were too frail or lived too far away to attend clinics and relied on regular home visits. These were time consuming and nurses in rural areas might have only been able to care for 40 active patients. New patients whose medications were being uptitrated were also time consuming. Trained staff in primary care could maybe take over this role with stable patients. The nurses’ opinion was that for the patient with advanced heart failure who needs more than the one initial home visit, an active caseload of 50 -60 was the ‘safe’ amount for providing good care. Nurses implied that a good scheme was to use clinics for the less ill, stable patients who are otherwise looked after by their community team, and review them at 6 monthly intervals. The nurses reported doing a lot of teaching to community teams on how to manage heart failure patients.

7.3.4 Do patients of South Asian origin get an equitable service?

We have noted (above) concerns about equity of access to heart failure specialist services for people of South Asian origin. In interview, it became evident that although patients and carers in three sites were satisfied with their HFSN service, it still appeared to be more of a medical focus with less of a holistic approach and psychological support than in other areas.
In the fourth site, patients of South Asian origin referred to the HFSN service were automatically handed over to a South Asian cardiac link nurse for their education and first home visit, and so the patients rarely saw a HFSN. This practice had continued even though the link nurse left and had not been replaced. However, it appears that the link nurse had been trained to provide equitable but culturally appropriate education, particularly about diet and exercise. She always liaised with the HFSNs after the home visit about medication changes, for which patients came to clinics. It appears that this nurse had been funded in an attempt to increase referrals of South Asian patients to cardiac rehabilitation and heart failure services, as the Trust was aware that this group were under-represented in these cardiac services. This referral to a different nurse may reflect a well intentioned but poor earlier management decision, as it resulted in an inequitable service for some of these patients. Care needs to be taken in future to ensure patients of South Asian origin are referred to, and receive, an equitable service.

**7.3.5 Did the nurses improve HRQOL in patients?**

There were significant improvements in overall physical and emotional scores over the 12 month period. To have had a significant improvement in score over 12 months in this patient group is an important result. As you would expect, at 6 month and 12 month follow up, higher NYHA class negatively affected the physical component scores. Combining this data with the qualitative data, we feel confident that being under the care of a HFSN significantly improved the HRQOL of their patients.

**7.3.6 Did the nurses improve patients’ knowledge of how to manage their condition?**

As we pointed out earlier, our patients had higher knowledge of how to manage their condition at the baseline measure than in other study populations. Surprisingly, there was a slight decrease in knowledge of self care behaviours over the 12 month period. This suggests that there is a need to reinforce self-care strategies at regular intervals. A system should be developed to ensure that stable patients discharged from the HFSN service to primary care still receive reinforcement of self-care strategies. The literature suggests that using a variety of reminders both written and verbal is worthwhile. Also, as there may be some cognitive impairment in patients, it is important to involve family in this education.

**7.3.7 Did the nurses improve patients’ anxiety and depression?**

Patients with heart failure have a high prevalence of depression with rates reported from 24% to >40%. According to the HADS, almost all of our patients were borderline or confirmed cases of anxiety. By the end of the year a significantly higher proportion had confirmed anxiety. Over the year, the proportions showing borderline or confirmed depression also increased significantly. Although these changes are significant statistically, they are very small and unlikely to be clinically significant. But worsening symptoms, having to change the way you live and lowering your expectations of life is known to increase depression. However, our patients had also had high numbers of co morbidities, a factor known to be linked with depression and poor quality of life. Poor mental health has a major effect on quality of life and predicts poor clinical outcomes and poor prognosis, and it is clear that the nurses were not able to improve the anxiety and depression of their patients. It is therefore important that they regularly assess the mental health of their patients and, where problems exist, to refer to psychology services (where these exist) or to the GP for medical therapy.
7.3.8 Did the nurses provide benefit to carers?

As measured by the SF12, carers had better physical health than the person they cared for, but this got worse over the year, and is poor compared to the general population. This may simply be due to ageing, or possibly due to having to do more of the physical tasks such as gardening, shopping, cleaning that the heart failure patient can no longer do. However, in the Care Giving Demands scale, carers did not report that they had a high level of difficulty in helping with the physical care of the patient. In retrospect we suspect that the measure we used is not very good at capturing the work that carers do and the items listed in the physical care giving scale perhaps do not reflect the activities that carers perform for heart failure patients. The role alteration scale was more useful, showing the negative impact caring has on work participation, social participation and the relationship with the spouse or relative. Overall, despite having piloted the questionnaire with a number of carers, we would agree with Karmilovich25 and Harkness26 that the tool did not adequately explain the stress and demands felt by carers. However, there was a correlation between high scores on all three domains of physical demands, role alteration and financial aspects of caring with poorer mental wellbeing in carers as measured by the SF12.

7.3.9 Why did we calculate ‘all cause’ readmissions?

We used all cause admissions for two reasons. Firstly, because some centres could only provide aggregate admissions, and secondly, all cause admissions account for any economic transfer of cost burden where, for example, heart failure admissions reduce but other admissions increase as a result of the service. From the data in the nurse database we were able to assess heart failure readmissions on an individual basis for each site (see Appendix 5), as well as non-heart failure admissions and all cause admissions. The average number of all cause admissions between April 05-March 06 was 35% less than in the 12 months prior to the nurses coming into post.

7.3.10 Did the nurses keep their patients out of hospital?

Patients in the nurses’ caseloads had fewer readmissions than other patients in their PCTs who had been discharged from hospital with a coding of heart failure, but did not see a heart failure specialist nurse. However, when patients were admitted they tended to be admitted for a longer duration (an average of 11.6 nights compared to 8.6 nights prior to the nurses coming into post). This is similar to the national average of 12.7 nights. The Department of Health report an average length of stay for a heart failure patient to be 12.2 nights in their Disease Management Toolkit. Nicol et al27 report that 99% are discharged within 10 days unless on Inotropes. In this study, those requiring longer admissions may have been very unwell and the length of stay therefore appropriate, compared to many patients unsupported by specialist follow up who have more, shorter but unnecessary hospital admissions.

7.3.11 How confident can we be that the nurses save money for their PCT?

We assessed the overall costs of providing the heart failure service and compared this with the potential cost savings the HFSNs bring to the NHS. However, we were looking at a 12 month period of HES data when the nurses were already in post, and possibly having an impact on admissions. In order to address this issue we modelled the activity within the PCTs using a proportional approach that estimated the activity in the absence of heart failure nurses. This produced an estimated saving of £1,826 per patient over and above the cost of the heart failure nurse. The model has been tested and appears to be robust, as the readmission rate in the model (estimating the readmission rate in the absence of HFSNs) is very close to the readmission rates prior to the nurses
coming into post. This increases the likelihood that the reduction in readmissions was due to HFSNs and that the resulting cost savings were valid.

7.4 Summary of the discussion points

HFSNs have the potential to make a difference to the care and lives of their patients, and save money through improving access to specialist follow up and reducing all cause readmissions. In order to optimise these benefits, services need to be flexible and have an individualised approach to assessment and intervention. This should involve collaboration and good communication between the HFSNs and all health and social care professionals.

There were many methods of service delivery according to case mix and geographical area, and no ‘one size fits all’ model of service or ideal ‘caseload’ can be recommended. An agreed guideline or discharge policy could potentially reduce nurses’ caseloads allowing more high risk patients to be seen. Although services should be set up and delivered according to the local context, a good model is where a cardiologist with a heart failure subspecialty and a GP with an interest in heart failure work with the HFSNs and the MDT.

Management and support for patients and caregivers not only reduces unplanned admissions to hospital, but can also improve aspects of health related quality of life. However, self-management education needs to be regularly reinforced and mental health needs should be better assessed and treated. In some areas the needs of ethnic minorities are not well served and unwarranted assumptions about what these groups need deny them access to services.

Improving the percentage of heart failure patients who receive good post diagnosis or discharge services may require appointing more HFSNs. Improvement may also be possible by making better use of other health professionals and triage to other services, with a system of half yearly review by a specialist nurse. Services should be part of a consistent integrated pathway of care, formalised in a written protocol, from diagnosis, through exacerbations to stabilisation, deterioration, supportive and palliative care to the management of death. This integrated model of care may be possible where multi professional teams work across services and manage patients on a care pathway agreed by local clinicians including heart failure specialist nurses.
References


13. Miles MB & Huberman AM. Qualitative data analysis. Thousand Oaks, CA; Sage, 1994


http://www.doh.gov.uk/nsf/coronarych6.htm

17. Horowitz CR, Rein S, and Howard L. A story of maladies, misconceptions and mishaps: effective

18. Karim K, Bailey M, and Tuna K. Non white ethnicity and the provision of specialist palliative care

19. Rogers AE, Addington-Hall JM, Abery AJ, McCoy ASM. Knowledge and communication

20. Bhopal R & Fischbach C. Prognosis for South Asian and white patients with heart failure in the
United Kingdom: counterintuitive findings on heart failure in South Asians may be artefactual. BMJ 2003; 327: 1405-6


302: 887-89

Nursing Administration 1998; 18 (11):5-6

Unpublished dissertation, University of Washington: Seattle

25. Karmilovich SE. Burden and stress associated with spousal caregiving for individuals with heart
failure. Progress in Cardiovascular Nursing 1994; 9(1):33-8

Living With heart Failure: A Review of Current Instruments. Journal of Cardiac Failure 2007;13 (7):
577-87

27. Nicol ED, Fittall B, Roughton M, Cleland JGF, Dargie H, Cowie MR. NHS heart failure survey:
a survey of acute heart failure admissions in England, Wales and Northern Ireland. Heart
2008;94(2):172-7

28. Chan DC, Heidenreich PA, Weinstein MC, Fonarow GC Heart failure disease management

Yamashita TE, Fairclough DL, Dy SM Symptoms, depression, and quality of life in patients with

management programmes in reducing hospital re-admission in older patients with heart failure:
a systematic review and meta analysis of published reports. Eur Heart J, 2004; 25:1570-95


32. Martensson J, Dracup K, Fridlund B. Decisive situations influencing spouses' support of patients
### Contents

| Model 1 | An example of an integrated heart failure care pathway (adapted from the Hastings, Bexhill & Rother PCT model) | 93 |
| Model 2 | Theoretical framework for qualitative study | 93 |
| Appendix 1 | Patient and carer questionnaires | 94 |
| Appendix 2 | Number of patients in Athena and recruited to survey by PCT | 114 |
| Appendix 3 | Non-participant sheet | 116 |
| Appendix 4 | Key variables in Athena data | 118 |
| Appendix 5 | Readmission for heart failure data | 120 |
| Appendix 6 | Profile of study sites and specialist nurses | 121 |
| Appendix 7 | Style of first interview by site | 128 |
| Appendix 8 | MDT Interview sample | 129 |
| Appendix 9 | HFSN Exit Interviews | 131 |
| Appendix 10 | South Asian patient interview sample | 132 |
| Appendix 11 | South Asian patient details | 133 |
| Appendix 12 | Exit Interviews topic guide | 137 |
| Appendix 13 | MDT Topic guide | 138 |
| Appendix 14 | PCT Lead guide | 138 |
| Appendix 15 | Topic guide for carers | 139 |
| Appendix 16 | Topic guide for patients | 140 |
Model 1: An example of an integrated heart failure care pathway (adapted from the Hastings, Bexhill & Rother PCT model)

- Presentation
  - Admission

- Gathering
  - Known HF
  - New HF
  - Discuss

- Diagnosis Prognosis
  - Management plan
    - Stable
    - Unstable
      - AHFN
      - CHFN
      - CRT/ICD

- Discharge planning
  - AHFN
  - CHFN

- Follow-up
  - AHFN
  - CHFN

- Review
  - CHFN

Key:
- AHFN: Acute heart failure nurse (hospital-based)
- CHFN: Community heart failure nurse
- CRT/ICD: Pacing and arrhythmia devices

Model 2: Accessing health care services (Aday 2003)
Appendix 1

Patient and carer questionnaires

Confidential
Evaluation of British Heart Foundation Heart Failure Nurse Service
Six month questionnaire for patients

Office use only (for designated person to complete)

Participant ID number: 

Date: 

Heart Failure Specialist Nurse Services: Development and Impact
v1 08/06/04
MREC Ref: 04/MRE07/14
PLEASE READ ALL THE INSTRUCTIONS BEFORE COMPLETING THE QUESTIONNAIRE

Thank you for agreeing to take part in this evaluation.

Please answer ALL the questions. Although it may seem that questions are asked more than once, it is still important that you answer every one.

If you find it difficult to answer a question, do the best you can.

Please follow the instructions for each section carefully.

For each section, if you are asked to put a cross in the box, please use a cross rather than a tick, as if you were filling out a ballot paper.

For example in the following question, if your answer to the question is yes, you should place a cross firmly in the box next to yes.

Do you drive a car ? Yes ☐
No ☐

If you are asked to circle a number, please use a circle rather than underlining a number.

For example, in the following question if you are asked ‘how happy are you today?’ where ‘1’ is ‘very unhappy’ and ‘5’ is ‘very happy’, if you feel neither happy nor unhappy you may wish to answer 3. You do this by clearly circling the number 3.

Very unhappy 1 2 3 4 5 Very happy

PLEASE USE A BLACK OR BLUE PEN.

Please do not use a pencil or any other coloured pen.

Please read all the instructions for each section.
This section contains different statements about living with and managing your heart failure. Respond to each statement by circling the number you think best applies to you. Every statement has a response that ranges from 1 'I completely agree' to 5 'I don't agree at all'. Even if you feel uncertain about a particular statement, circle the number that you feel is most true of you. (For each question circle the number corresponding to your answer)

<table>
<thead>
<tr>
<th>Statement</th>
<th>I completely agree</th>
<th>I don't agree at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I weigh myself every day.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>2. If I get short of breath, I take it easy.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>3. If my shortness of breath increases, I contact my doctor or nurse.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>4. If my feet/legs become more swollen than usual, I contact my doctor or nurse.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>5. If I gain 2 kg (4 lbs) in 1 week, I contact my doctor or nurse.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>6. I limit the amount of fluids I drink (not more than 1.5 - 2 litres (3-4 pints) per day)</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>7. I take a rest during the day.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>8. If I experience increased fatigue, I contact my doctor or nurse.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>9. I eat a low salt diet.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>10. I take my medication as prescribed.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>11. I get a flu shot every year.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
<tr>
<td>12. I exercise regularly.</td>
<td>1</td>
<td>2 3 4 5</td>
</tr>
</tbody>
</table>
These questions concern how your heart failure (heart condition) has prevented you from living as you wanted during the last month. The questions listed below describe different ways some people are affected. If you are not sure whether a question applies to you or is not related to your heart failure circle ‘0’ (No or not applicable), for that question and go on to the next question. If a question does apply to you, then circle the number indicating how much it has prevented you from living as you wanted, where '1' is ‘very little’ and '5' is ‘very much’.  

<table>
<thead>
<tr>
<th>No or not applicable</th>
<th>Very little</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Causing swelling in your ankles, legs, etc? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Making you sit or lie down to rest during the day? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Making your walking about or climbing stairs difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Making your working about the house or stairs difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Making your going places away from home difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Making your sleeping well at night difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Making your relating to or doing things with your friends or family difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Making your working to earn a living difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Making your recreational pastimes, sports or hobbies difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Making your sexual activities difficult? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Making you eat less of the foods you like? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Making you short of breath? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Making you tired, fatigued or low on energy? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Making you stay in hospital? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Costing you money on medical care? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Giving you side effects from your medication? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Making you feel you are a burden to your family or friends? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Making you feel a loss of self-control in your life? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Making you worry? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Making it difficult for you to concentrate or remember things? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Making you feel depressed? 1 2 3 4 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following questions ask about your views about your health. This section will help us understand more about how heart failure patients feel and how well they are able to do their usual activities. Please answer every question. If you are unsure how to answer a question, please give the best answer that you can. Please circle one number for each question.

1. In general, would you say your health is? (please circle one number only)

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. During a typical day does your health limit you in moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf? If so, how much? (please circle one number only)

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

3. During a typical day does your health limit you in climbing several flights of stairs? If so, how much? (please circle one number only)

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

4. During the past 4 weeks, how much time have you accomplished less than you would like in regular daily activities as a result of your physical health? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

5. During the past 4 weeks, how much time have you been limited in performing any kind of work or other regular daily activities as a result of your physical health? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

6. During the past 4 weeks, how much time have you accomplished less than you would have liked in your work or any other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
7. During the **past 4 weeks**, how much time have you done work or other activities less carefully than usual **as a result of any emotional problems** (such as feeling depressed or anxious)? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5

8. During the **past 4 weeks**, how much did pain interfere with your normal work (both outside the home and housework)? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5

9. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** have you felt calm and peaceful? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5

10. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** did you have a lot of energy? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5

11. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** have you felt downhearted and low? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5

12. During the **past 4 weeks** how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting friends, relatives etc.)? *(please circle one number only)*

All of the time  Most of the time  Some of the time  A little of the time  None of the time
1  2  3  4  5
The following questions are designed to assess how you have been feeling in the past 7 days, rather than your ability to do things due to your heart failure. Please read each question and place a cross in the box next to the reply which comes closest to how you have been feeling during the past week. Do not take too long over your replies: your immediate reaction to each question will probably be more accurate than a long thought out response.

I feel tense or 'wound up':
Most of the time
A lot of the time
Time to time, occasionally
Not at all

I still enjoy the things I used to enjoy:
Definitely as much
Not quite so much
Only a little
Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:
Very definitely and quite badly
Yes, but not too badly
A little but it doesn’t worry me
Not at all

I can laugh and see the funny side of things:
As much as I always could
Not quite so much now
Definitely not so much now
Not at all

Worrying thoughts go through my mind:
A great deal of the time
A lot of the time
From time to time, but not too often
Only occasionally

I feel cheerful:
Not at all
Not often
Sometimes
Most of the time

I can sit at ease and feel relaxed:
Definitely
Usually
Not often
Not at all

I feel as if I am slowed down:
Nearly all of the time
Very often
Sometimes
Not at all

I get a sort of frightened feeling like 'butterflies' in the stomach:
Not at all
Occasionally
Quite often
Very often

I have lost interest in my appearance:
Definitely
I don’t take care as much as I should
I may not take as much care
I take just as much care as ever

I feel restless as if I have to be on the move:
Very much indeed
Quite a lot
Not very much
Not at all

I look forward with enjoyment to things:
As much as I ever did
Rather less than I used to
Definitely less than I use to
Hardly at all

I get sudden feelings of panic:
Very often indeed
Quite often
Not very often
Not at all

I can enjoy a good book or radio or TV programme:
Often
Sometimes
Not often
Not at all
These questions ask what you think of your last visit to (or by) the heart failure specialist nurse. Please answer all of the questions. Your answers will be kept entirely confidential and will not be shown to the nurse so feel free to say what you wish. Some of the questions will appear similar. This is deliberate and is necessary to make sure they are reliable. Please answer them all. For each question please circle the answer that is the closest to what you think. ‘Neutral’ means you have no feelings either way.

For example
“This nurse was unhelpful” Strongly agree / Agree [Neutral] Disagree / Strongly Disagree

1.  I am totally satisfied with my visit to (or by) the nurse.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

2.  This nurse was very careful to check everything when examining me.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

3.  I will follow this nurse’s advice because I think he/she is absolutely right.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

4.  I felt able to tell this nurse about very personal things.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

5.  I am happy to see the nurse rather than the doctor for my present problem.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

6.  This nurse told me everything about my problem.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

7.  Some things about my consultation with the nurse could be better.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

8.  Following this consultation with the nurse I do not feel I need to see the doctor for this problem.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

9.  This nurse examined me very thoroughly.
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

10. I would use the services of this nurse again.
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

11. The time I was allowed to spend with the nurse was not long enough to deal with everything I wanted.
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

12. I understand my illness much better after seeing this nurse.
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

13. This nurse was interested in me as a person not just my illness.
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

14. I wish it had been possible to spend a little longer with the nurse.
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree
15. I would find it difficult to tell this nurse about some private things.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

Do you have any other comments about the consultation with the specialist nurse?

(Please enter your comments in the box below)
Confidential
Evaluation of British Heart Foundation Heart Failure Nurse Service
Six month questionnaire for carers

Office use only (for designated person to complete)

Participant ID number: [ ]

Date: [ ] / [ ] / [ ]

day  month  year

Heart Failure Specialist Nurse Services: Development and Impact
v1 08/06/04
MREC Ref: 04/MRE07/14
PLEASE READ ALL THE INSTRUCTIONS BEFORE COMPLETING THE QUESTIONNAIRE

Thank you for agreeing to take part in this evaluation.

Please answer ALL the questions. Although it may seem that questions are asked more than once, it is still important that you answer every one.

If you find it difficult to answer a question, do the best you can.

Please follow the instructions for each section carefully.

For each section, if you are asked to put a cross in the box, please use a cross rather than a tick, as if you were filling out a ballot paper.

For example in the following question, if your answer to the question is yes, you should place a cross firmly in the box next to yes.

Do you drive a car? Yes ☐ No ☑

If you are asked to circle a number, please use a circle rather than underlining a number.

For example, in the following question if you are asked ‘how happy are you today?’ where ‘1’ is ‘very unhappy’ and ‘5’ is ‘very happy’, if you feel neither happy nor unhappy you may wish to answer 3. You do this by clearly circling the number 3.

Very unhappy 1 2 3 4 5 Very happy

PLEASE USE A BLACK OR BLUE PEN.

Please do not use a pencil or any other coloured pen.

Please read all the instructions for each section.
The following questions ask about your views about your health. This section will help us understand more about how carers feel and how well they are able to do their usual activities. Please answer every question. If you are unsure how to answer a question, please give the best answer that you can. Please circle one number for each question.

1. **In general**, would you say your health is: (please circle one number only)

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. During a typical day does **your health** limit you in **moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling or playing golf? If so, how much? (please circle one number only)

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

3. During a typical day does **your health** limit you in climbing **several** flights of stairs? If so, how much? (please circle one number only)

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

4. During the **past 4 weeks**, how much time have you accomplished less than you would like in regular daily activities as a result of your **physical health**? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

5. During the **past 4 weeks**, how much time have you been limited in performing any kind of work or other regular daily activities as a result of your **physical health**? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

6. During the **past 4 weeks**, how much time have you accomplished less than you would have liked in your work or any other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (please circle one number only)

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
7. During the **past 4 weeks**, how much time have you done work or other activities less carefully than usual as a result of any emotional problems (such as feeling depressed or anxious)? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

8. During the **past 4 weeks**, how much did pain interfere with your normal work (both outside the home and housework)? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

9. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** have you felt calm and peaceful? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

10. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** did you have a lot of energy? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

11. This question is about how you feel and how things have been with you **during the last month**. Please give the one answer that comes closest to the way you have been feeling. How much during the **last month** have you felt downhearted and low? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

12. During the **past 4 weeks** how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)? *(please circle one number only)*

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Below is a list of phrases that describe situations some men and women experience when their family member or relative has a health problem. Please read each item carefully. Circle 'yes' or 'no' to indicate if you have experienced any of these over the past month, including today. If you circle 'yes', please circle one number which best describes the difficulty of this experience for you, where 1 indicates 'not at all difficult' and 5 indicates 'extremely difficult'.

<table>
<thead>
<tr>
<th>Physical Caregiving</th>
<th>Have you had the following experience</th>
<th>How difficult is this for you to manage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Meals and feeding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Helping with his/her food.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. Preparing meals.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. Planning meals.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Intimate care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Helping with dressing.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. Helping with bathing.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. Helping with using toilet, bedpan or commode.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4. Helping with appearance such as combing his/her hair, or brushing teeth.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td><strong>Walking and transfers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Helping with walking across the room.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>2. Helping him/her get in and out of bed, chair or couch.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>3. Driving him/her wherever he/she needs to go.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>4. Helping him/her to use the phone.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
<tr>
<td>5. Helping him/her to get in a comfortable position in bed.</td>
<td>Yes</td>
<td>1 2 3 4 5</td>
</tr>
</tbody>
</table>
### Treatments

<table>
<thead>
<tr>
<th>Experience</th>
<th>Yes</th>
<th>No</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Helping him/her to take medication.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Preparing medications.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Contacting the doctor or nurse for medication needs.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Purchasing medications.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Assessing medication needs.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Helping with his/her treatment.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Contacting the doctor or nurse for treatment needs.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Assessing treatment needs.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Keeping him/her comfortable and without pain.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Supervision/Responsibility

<table>
<thead>
<tr>
<th>Experience</th>
<th>Yes</th>
<th>No</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Being available 24 hours a day.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Arranging for someone to stay when I go out.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Feeling responsible for his/her care and well-being.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Watching him/her become more ill, but not able to do anything about it.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Not knowing if I will be able to handle his/her care in the future.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

### Rest

<table>
<thead>
<tr>
<th>Experience</th>
<th>Yes</th>
<th>No</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Helping him/her during the night.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Giving treatments or medications during the night.</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Have you had the following experience | How difficult is this for you to manage
--- | ---
**New skills**
1. Learning how to give physical care. | Yes | No | 1 | 2 | 3 | 4 | 5
2. Learning how to give treatments. | Yes | No | 1 | 2 | 3 | 4 | 5
3. Learning how to give medication (pills, injections or suppositories). | Yes | No | 1 | 2 | 3 | 4 | 5

**Role alterations**

**Work participation**
1. I am currently taking time off my job. | Yes | No | 1 | 2 | 3 | 4 | 5

**Social participation**
1. I am able to participate in the social and recreational activities I enjoy. | Yes | No | 1 | 2 | 3 | 4 | 5
2. I am unable to go out and participate in activities that I am interested in. | Yes | No | 1 | 2 | 3 | 4 | 5

**Financial alterations**
1. There is enough money for the health care bills. | Yes | No | 1 | 2 | 3 | 4 | 5
2. There isn’t enough money to meet our expenses. | Yes | No | 1 | 2 | 3 | 4 | 5
Only answer the following questions if the person you care for is your **spouse or partner**.

<table>
<thead>
<tr>
<th>Have you had the following experience</th>
<th>How difficult is this for you to manage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My partner and I can no longer talk like we used to.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>2. I share my problems and concerns with my partner.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>3. My partner and I express physical affection for each other.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>4. My partner and I have intimate time together.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>5. My partner is just not the person he/she once was.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>6. My partner and I no longer participate in household leisure activities such as playing cards and board games.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>7. My partner and I no longer participate in social activities such as going out to dinner or to a movie.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>8. We are able to entertain friends in our home despite my partner’s physical care needs.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>9. There isn’t enough money to meet the costs of caring for my partner at home.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
<tr>
<td>10. There is less money to meet our expenses since my partners illness.</td>
<td>Yes No 1 2 3 4 5</td>
</tr>
</tbody>
</table>
These questions ask what you think of the last visit to (or by) the heart failure specialist nurse for the person you care for. Please answer all of the questions. Your answers will be kept entirely confidential and will not be shown to the nurse so feel free to say what you wish. Some of the questions will appear similar. This is deliberate and is necessary to make sure they are reliable. Please answer them all. **For each question please circle the answer that is the closest to what you think.** 'Neutral' means you have no feelings either way.

**For example**

*This nurse was unhelpful*  
Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

1. I am totally satisfied with the visit to (or by) the nurse.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

2. This nurse was very careful to check everything when examining my relative/partner.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

3. I will follow this nurse's advice because I think he/she is absolutely right.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

4. I felt able to tell this nurse about very personal things.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

5. I am happy to see the nurse rather than the doctor for my present problem.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

6. This nurse told me everything about my relative/partner's problem.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

7. Some things about my consultation with the nurse could be better.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

8. Following this consultation with the nurse I do not feel I need to see the doctor for this problem.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

9. This nurse examined my relative/partner very thoroughly.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

10. I would use the services of this nurse again.  
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

11. The time I was allowed to spend with the nurse was not long enough to deal with everything I wanted.  
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

12. I understand my relative/partner's illness much better after seeing this nurse.  
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

13. This nurse was interested in me as a person not just my relative/partner's illness.  
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

14. I wish it had been possible to spend a little longer with the nurse.  
    Strongly agree / Agree / Neutral / Disagree / Strongly Disagree
15. I would find it difficult to tell this nurse about some private things.  
   Strongly agree / Agree / Neutral / Disagree / Strongly Disagree

Do you have any other comments about the consultation with the specialist nurse?
(Please enter your comments in the box below)
Appendix 2

Number of patients in Athena & recruited to survey by PCT

Sources of Data

**Primary Care Trust Level Data**
Details of admissions and readmissions for heart failure over the retrospective and prospective period are derived from annual Hospital Episode Statistics (Department of Health) for the appropriate accounting period. Individual patients are identified using an anonymised unique identifier (HESID) and PCT attribution is achieved using PCT of normal residence (RESPCT). (appendix 5)

**Heart Failure Nurse Level Data**
Heart failure nurse caseloads are established using the Athena database (Capturebeat Ltd). Data is anonymised prior to receipt and key variables included in the analysis (Appendix 4).

**Participants not ineligible or not approached**
Each nurse provided details of any patient who was not eligible or who was not approached for participation in the survey on a specially designed form (Appendix 3).

**Patient included in the survey**
Patients included in the survey were followed up at 6 months and 12 months post recruitment using a questionnaire specifically designed for the study (Appendix 1).
<table>
<thead>
<tr>
<th>PCT Name</th>
<th>Athena Caseload</th>
<th>Not Approached</th>
<th>Non-Consenting Patients</th>
<th>Consenting Patients</th>
<th>Consenting Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnsley PCT</td>
<td>188</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Bexhill &amp; Rother PCT, Hastings &amp; St Leonards PCT</td>
<td>584</td>
<td>12</td>
<td>0</td>
<td>33</td>
<td>16</td>
</tr>
<tr>
<td>Bromley PCT, Lewisham PCT</td>
<td>359</td>
<td>12</td>
<td>10</td>
<td>43</td>
<td>9</td>
</tr>
<tr>
<td>Cannock Chase PCT, SW Staffordshire PCT</td>
<td>288</td>
<td>1</td>
<td>1</td>
<td>33</td>
<td>21</td>
</tr>
<tr>
<td>Carlisle &amp; District PCT, West Cumbria PCT, Eden Valley PCT</td>
<td>267</td>
<td>1</td>
<td>1</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Croydon PCT</td>
<td>195</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Doncaster East PCT, Doncaster West PCT, Doncaster Central PCT</td>
<td>397</td>
<td>6</td>
<td>8</td>
<td>51</td>
<td>22</td>
</tr>
<tr>
<td>Durham Dales PCT, Sedgefield PCT &amp; Darlington PCT</td>
<td>266</td>
<td>9</td>
<td>6</td>
<td>44</td>
<td>19</td>
</tr>
<tr>
<td>Erewash PCT, Derby Dales &amp; S Derbys PCT, Greater Derby PCT, Central Derby PCT, Amber Valley PCT</td>
<td>1003</td>
<td>0</td>
<td>0</td>
<td>12</td>
<td>5</td>
</tr>
<tr>
<td>Harrow PCT</td>
<td>128</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Hinkley &amp; Bosworth PCT, Charnwood &amp; NW Leics PCT</td>
<td>268</td>
<td>8</td>
<td>3</td>
<td>39</td>
<td>10</td>
</tr>
<tr>
<td>Kensington &amp; Chelsea PCT, Westminster PCT</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Mansfield PCT, Newark &amp; Sherwood PCT, Ashfield PCT</td>
<td>195</td>
<td>7</td>
<td>2</td>
<td>64</td>
<td>39</td>
</tr>
<tr>
<td>Newcastle PCT, Northumberland Care Trust, North Tyneside PCT</td>
<td>572</td>
<td>92</td>
<td>4</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td>Oldham PCT, Bury PCT, Rochdale PCT, Heywood &amp; Middleton PCT, North Manchester PCT</td>
<td>398</td>
<td>7</td>
<td>9</td>
<td>114</td>
<td>27</td>
</tr>
<tr>
<td>Scarborough, Whitby &amp; Ryedale PCT, Yorkshire Wolds &amp; Coast PCT</td>
<td>384</td>
<td>54</td>
<td>3</td>
<td>70</td>
<td>34</td>
</tr>
<tr>
<td>SE Oxon PCT, Cherwell Vale PCT, NE Oxon PCT, Oxford City PCT, SW Oxon PCT</td>
<td>326</td>
<td>20</td>
<td>0</td>
<td>52</td>
<td>10</td>
</tr>
<tr>
<td>Selby &amp; York PCT</td>
<td>332</td>
<td>15</td>
<td>0</td>
<td>35</td>
<td>15</td>
</tr>
<tr>
<td>South &amp; East Dorset PCT, Poole PCT</td>
<td>144</td>
<td>4</td>
<td>1</td>
<td>47</td>
<td>16</td>
</tr>
<tr>
<td>South Stoke PCT, Staffordshire Moorlands PCT, North Stoke PCT, Newcastle under Lyme PCT</td>
<td>427</td>
<td>4</td>
<td>8</td>
<td>51</td>
<td>23</td>
</tr>
<tr>
<td>South Worcestershire PCT</td>
<td>450</td>
<td>3</td>
<td>0</td>
<td>60</td>
<td>1</td>
</tr>
<tr>
<td>Southampton City PCT, New Forest PCT</td>
<td>162</td>
<td>5</td>
<td>0</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Trafford North PCT, South Manchester PCT</td>
<td>233</td>
<td>3</td>
<td>2</td>
<td>35</td>
<td>20</td>
</tr>
<tr>
<td>W Glos NHS PCT, Cotswold &amp; Vale NHS PCT, Cheltenham &amp; Tewkesbury NHS PCT</td>
<td>503</td>
<td>1</td>
<td>2</td>
<td>23</td>
<td>12</td>
</tr>
<tr>
<td>West Cornwall PCT, Central Cornwall PCT</td>
<td>621</td>
<td>2</td>
<td>4</td>
<td>63</td>
<td>21</td>
</tr>
<tr>
<td>Wolverhampton City PCT</td>
<td>662</td>
<td>1</td>
<td>2</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>9354</strong></td>
<td><strong>267</strong></td>
<td><strong>69</strong></td>
<td><strong>954</strong></td>
<td><strong>342</strong></td>
</tr>
</tbody>
</table>
Appendix 3

Non-participant sheet

A study of the development and impact of the British Heart Foundation and Big Lottery Fund Heart Failure Specialist Nurse Services in England

DETAILS OF PATIENT NON-PARTICIPANTS
Guidance for Specialist Nurses

It is important that the research team understand reasons for non-participation. Please ensure that this form is completed for all patient non-participants. This includes:

- When a patient is not eligible
- When a patient meets the inclusion criteria but declines study information pack
- When you decide not to provide study information to patient

Nurse ID

Please insert

Sex of patient

Please circle

Male  Female

Date of birth of patient

Please insert

Patient lives with:

Please circle or circle and insert detail:

Alone
Spouse
Partner
Daughter
Son
Other relative (please specify) ...........................................................
Other (please specify) ...........................................................

Does the patient meet inclusion criteria?

Please tick box:

Confmed diagnosis of heart failure
Living in the community
Acceptance of Specialist Nurse service
### Reason for non-participation

*Please tick boxes and insert detail where required:*

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient not eligible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>= Written case record of cognitive deficit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>= Unable to make daily decisions about their own care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>= In nursing home care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient non-English speaking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Given study information in own language and interview response form</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If possible, insert reason why

- The patient did not want the study information pack

Insert reason why

- I did not give the patient a study information pack

### Where did you try to recruit this patient/ decide not to recruit this patient *(please tick box)*?

<table>
<thead>
<tr>
<th>Location</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Out-patient clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In hospital ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>At home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please insert</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Please write the main co-morbidities that this person has:


### Tick any of the following that apply to this person:

<table>
<thead>
<tr>
<th>Trait</th>
<th>No</th>
<th>Former</th>
<th>Current</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overweight</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol XS</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please circle NYHA status at first meeting with patient:

I  II  III  IV

### PLEASE RETURN COMPLETED FORMS TO:

Dr Karen Spilsbury (Research Fellow), Department of Health Sciences, University of York, Area 2 (1st Floor) Seebohm Rowntree Building, YORK YO10 5DD
Appendix 4

Key variables in Athena Data

Evaluation of British Heart Foundation and Big Lottery Fund

Heart Failure Specialist Nurse Service

Aim 1 and Aim 2 audit data collection: York Trials Unit

Aim 1 and Aim 2 of the service are:

1. To improve patient access to specialist heart failure care with particular reference to community based services.
2. To reduce emergency admissions.

Minimum data needed for evaluation: Historical data from PCT/Hosp on admissions and readmissions/ outpatient clinic appts / % of pts on optimal doses of ACE and BB.

HF mgt data: This information needs to collected quarterly from the specialist nurses and be able to be summarised into a print out for each nurse on how many patients in her caseload and how many contacts she has had over the period and of what type (new, repeat, where).

Code to identify HF specialist nurse

Patient hospital code (or read code)

Demographic information

<table>
<thead>
<tr>
<th>Postcode</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP postcode</td>
</tr>
<tr>
<td>Age at presentation</td>
</tr>
<tr>
<td>Sex – male/ female</td>
</tr>
<tr>
<td>Ethnic Origin –</td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Black Caribbean</td>
</tr>
<tr>
<td>Black African</td>
</tr>
<tr>
<td>Black Other</td>
</tr>
<tr>
<td>Indian</td>
</tr>
<tr>
<td>Pakistani</td>
</tr>
<tr>
<td>Bangladeshi</td>
</tr>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Other (state)</td>
</tr>
<tr>
<td>Marital status –</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Married</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Divorced</td>
</tr>
<tr>
<td>Married but separated</td>
</tr>
<tr>
<td>Other (state)</td>
</tr>
<tr>
<td>Lives with –</td>
</tr>
<tr>
<td>Alone</td>
</tr>
<tr>
<td>Spouse</td>
</tr>
<tr>
<td>Child</td>
</tr>
<tr>
<td>Sibling (brother/ sister)</td>
</tr>
<tr>
<td>Friend</td>
</tr>
<tr>
<td>Other relative (state)</td>
</tr>
<tr>
<td>Other (state)</td>
</tr>
<tr>
<td>Lives in –</td>
</tr>
<tr>
<td>----------------------------</td>
</tr>
<tr>
<td>Own home</td>
</tr>
<tr>
<td>Relatives home</td>
</tr>
<tr>
<td>Sheltered housing</td>
</tr>
<tr>
<td>Residential housing</td>
</tr>
<tr>
<td>Nursing home</td>
</tr>
<tr>
<td>Other (state)</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place of contact –</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s home</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital outpatient clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community outpatient clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (state)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NYHA classification</th>
<th></th>
<th></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Number of co-morbidities (choose from):</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Atrial fibrillation</td>
<td></td>
</tr>
<tr>
<td>Chronic renal failure</td>
<td></td>
</tr>
<tr>
<td>Ischaemic Heart Disease</td>
<td></td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACE inhibitors –</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes/no/titrating/intolerant/</td>
<td></td>
</tr>
<tr>
<td>optimal dose reached.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Beta Blockers –</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>yes/no/titrating/intolerant/</td>
<td></td>
</tr>
<tr>
<td>optimal dose reached.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Date of re-admission</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Worsening heart failure (unplanned)</td>
<td></td>
</tr>
<tr>
<td>Heart failure related planned admission</td>
<td></td>
</tr>
<tr>
<td>Other cardiac reason</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 5

### Readmissions for heart failure data

<table>
<thead>
<tr>
<th>PCT Name</th>
<th>Retrospective HF Readmissions</th>
<th>Prospective HF Readmissions</th>
<th>Change in Readmissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnsley PCT</td>
<td>34</td>
<td>15</td>
<td>-55</td>
</tr>
<tr>
<td>Bexhill &amp; Rother PCT, Hastings &amp; St Leonards PCT</td>
<td>26</td>
<td>14</td>
<td>-48</td>
</tr>
<tr>
<td>Bromley PCT, Lewisham PCT</td>
<td>20</td>
<td>15</td>
<td>-25</td>
</tr>
<tr>
<td>Cannock Chase PCT, SW Staffordshire PCT</td>
<td>23</td>
<td>15</td>
<td>-36</td>
</tr>
<tr>
<td>Carlisle &amp; District PCT, West Cumbria PCT, Eden Valley PCT</td>
<td>26</td>
<td>17</td>
<td>-34</td>
</tr>
<tr>
<td>Croydon PCT</td>
<td>16</td>
<td>14</td>
<td>-10</td>
</tr>
<tr>
<td>Doncaster East PCT, Doncaster West PCT, Doncaster Central PCT</td>
<td>29</td>
<td>15</td>
<td>-49</td>
</tr>
<tr>
<td>Durham Dales PCT, Sedgefield PCT &amp; Darlington PCT</td>
<td>23</td>
<td>17</td>
<td>-26</td>
</tr>
<tr>
<td>Erewash PCT, Derby Dales &amp; S Derbys PCT, Greater Derby PCT, Central Derby PCT, Amber Valley PCT</td>
<td>30</td>
<td>19</td>
<td>-37</td>
</tr>
<tr>
<td>Harrow PCT</td>
<td>76</td>
<td>30</td>
<td>-61</td>
</tr>
<tr>
<td>Hinkley &amp; Bosworth PCT, Charnwood &amp; NW Leics PCT</td>
<td>41</td>
<td>18</td>
<td>-56</td>
</tr>
<tr>
<td>Kensington &amp; Chelsea PCT, Westminster PCT</td>
<td>20</td>
<td>18</td>
<td>-8</td>
</tr>
<tr>
<td>Mansfield PCT, Newark &amp; Sherwood PCT, Ashfield PCT</td>
<td>22</td>
<td>14</td>
<td>-34</td>
</tr>
<tr>
<td>Newcastle PCT, Northumberland Care Trust, North Tyneside PCT</td>
<td>31</td>
<td>17</td>
<td>-46</td>
</tr>
<tr>
<td>Oldham PCT, Bury PCT, Rochdale PCT, Heywood &amp; Middleton PCT, North Manchester PCT</td>
<td>32</td>
<td>17</td>
<td>-47</td>
</tr>
<tr>
<td>Scarborough, Whitby &amp; Ryedale PCT, Yorkshire Wolds &amp; Coast PCT</td>
<td>40</td>
<td>17</td>
<td>-59</td>
</tr>
<tr>
<td>SE Oxon PCT, Cherwell Vale PCT, NE Oxon PCT, Oxford City PCT, SW Oxon PCT</td>
<td>20</td>
<td>15</td>
<td>-27</td>
</tr>
<tr>
<td>Selby &amp; York PCT</td>
<td>23</td>
<td>17</td>
<td>-26</td>
</tr>
<tr>
<td>South &amp; East Dorset PCT, Poole PCT</td>
<td>30</td>
<td>12</td>
<td>-60</td>
</tr>
<tr>
<td>South Stoke PCT, Staffordshire Moorlands PCT, North Stoke PCT, Newcastle under Lyme PCT</td>
<td>30</td>
<td>19</td>
<td>-36</td>
</tr>
<tr>
<td>South Worcestershire PCT</td>
<td>33</td>
<td>17</td>
<td>-48</td>
</tr>
<tr>
<td>Southampton City PCT, New Forest PCT</td>
<td>24</td>
<td>14</td>
<td>-43</td>
</tr>
<tr>
<td>Trafford North PCT, South Manchester PCT</td>
<td>28</td>
<td>21</td>
<td>-24</td>
</tr>
<tr>
<td>W Glos NHS PCT, Cotswold &amp; Vale NHS PCT, Cheltenham &amp; Tewkesbury NHS PCT</td>
<td>25</td>
<td>17</td>
<td>-33</td>
</tr>
<tr>
<td>West Cornwall PCT, Central Cornwall PCT</td>
<td>24</td>
<td>11</td>
<td>-54</td>
</tr>
<tr>
<td>Wolverhampton City PCT</td>
<td>24</td>
<td>14</td>
<td>-42</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>29</strong></td>
<td><strong>17</strong></td>
<td><strong>-43</strong></td>
</tr>
</tbody>
</table>
Appendix 6

Profile of study sites and specialist nurses

**Study site 25**

PCTs/ Acute Trusts: 1 PCT; 1 Acute Trust  
Existing HF services: HFSN service piloted in secondary care clinic + limited ward service.  
(Current BHF HFSN piloted services + community service in the locality)  
Geography: Geographically large; City and rural  
HF population: Estimated prevalence HF patients: 3,000 (1-2% population)  
PCT population: High numbers of elderly patients

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>51</td>
<td>37</td>
<td>F</td>
<td>Oct 2004</td>
<td>G</td>
<td>PT</td>
<td>1989</td>
<td>RN Diploma Nursing BSc Health Studies</td>
<td>2 ½ years acute general care 11 years acute coronary care 3 years cardiac rehab</td>
</tr>
<tr>
<td>52</td>
<td>51</td>
<td>M</td>
<td>Sept 2004</td>
<td>G</td>
<td>FT</td>
<td>1975</td>
<td>SRN RMN Diploma Critical Care</td>
<td>12 years acute psychiatry 2 years acute general care 6 years intensive care/ A&amp;E 10 years acute coronary care</td>
</tr>
<tr>
<td>7</td>
<td>38</td>
<td>F</td>
<td>July 2004</td>
<td>G</td>
<td>PT</td>
<td>1988</td>
<td>RN BSc Health Care Sciences ENB 254 Cardiac Care ENB 100 Intensive Care City &amp; Guilds 2307 Teaching &amp; Assessing</td>
<td>2 years acute general care 2 years intensive care 9 years cardiothoracic + ICU 2 years heart failure nurse (hospital) 1 year study + work abroad</td>
</tr>
<tr>
<td>8</td>
<td>42</td>
<td>F</td>
<td>June 2004</td>
<td>G</td>
<td>FT</td>
<td>1984</td>
<td>RN ENB 124 Coronary Care ENB 998 Teaching &amp; Assessing Diploma Health Studies Await Degree Health Studies results</td>
<td>1 year acute general care 1 year cardiology 11 years coronary care 3 years intensive care 1 years research nurse 3 years heart failure specialist (hospital)</td>
</tr>
</tbody>
</table>

* Ethnicity not reported to protect anonymity of ethnic minority group nurses
### Study site 26

**PCTs / Acute Trusts:** 3 PCTs; 2 Acute Trusts  
**Existing HF services:** HF services based in secondary care. Existing community cardiology nursing teams  
**Geography:** Rural and urban  
**HF population:** Estimated prevalence HF patients: 19,000 (1.3% population)  
**PCT population:** Significant numbers of residents from ethnic minority groups

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
</table>
| 4  | 45  | F      | Aug 2004  | G     | PT    | 1980      | SEN SRN DN      | 1 year acute general care  
7 years cardiothoracic  
12 years district nurse  
2 years cardiac rehab  
(commercial) 2 years conversion to RN 1 years DN training |
| 6  | 32  | F      | Aug 2004  | G     | FT    | 1993      | BSc Nursing Studies  
BSc Community Specialist/ District Nursing ENB 998  
Teaching & Assessing Nurse prescribing  
Palliative Care | 1 year care elderly 2 years community nurse 7 years district nurse 1 year DN training |
| 5  | 38  | F      | Aug 2004  | G     | FT    | 1988      | ENB 249  
Cardiothoracic Nursing ENB 998 Teaching & Assessing | 1 year general acute care  
1 year cardiothoracic surgery 6 years cardiology  
6 years research nurse cardiology 2 years patient care advisor  
(cardiothoracic) |
| 3  | 46  | F      | Aug 2004  | G     | PT    | 1979      | RN RM RHV        | 4 years general acute care  
4 years cardiology 6 years  
community health visitor  
1 years cardiac rehab  
nurse (commercial) * time for family |
### Study site 2

**PCTs / Acute Trusts:** 2 PCTs; 1 Acute Trust

**Existing HF services:** 1 consultant nurse-led clinic in Acute Trust. 1 community nurse ‘hospital at home’. Primary care CHD nurses

**Geography:** Inner city/ urban

**HF population:** Estimated prevalence HF patients: 18,896 (4% population)

**PCT population:** Areas of significant deprivation. High ethnic minority groups

(51% Brent/ 39% Harrow). Large, highly mobile, diverse community. 25,000 refugees (46 countries)

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>72</td>
<td>28</td>
<td>F</td>
<td>Oct 2004</td>
<td>G</td>
<td>FT</td>
<td>2000</td>
<td>BSc Nursing Diploma Managing Diabetes/ CHD Practice  Nursing &amp; Family Planning Extended &amp; Supplementary prescribing Trained facilitator initiation of insulin Certificate Cardiovascular Nursing</td>
<td>2 years practice nurse (chronic disease) 1 year cardiac nurse (community) 1 year cardiac rehab lead (community)</td>
</tr>
<tr>
<td>64</td>
<td>43</td>
<td>F</td>
<td>Oct 2004</td>
<td>G</td>
<td>FT</td>
<td>1984</td>
<td>SEN ENB 166 Cardiac Care RN ENB 254 Cardiology ENB 998 Teaching &amp; Assessing ENB 928 Diabetes BSc Nursing (cardiac /respiratory pathway)</td>
<td>3 years general acute care 13 years cardiology 2 years CHD nurse (community) 2 years Cardiac rehab specialist nurse (acute)</td>
</tr>
<tr>
<td>80</td>
<td>44</td>
<td>F</td>
<td>July 2005</td>
<td>G</td>
<td>FT</td>
<td>1983</td>
<td>RN ENB 100 Critical Care ENB 998 Teaching &amp; Assessing  BSc Cardio Respiratory Nursing Independent/ Supplementary Prescribing Health Education Certificate</td>
<td>11 years cardiology/ HDU 5 years Heart Failure CNS (secondary care)</td>
</tr>
</tbody>
</table>
### Study site 22

PCTs / Acute Trusts: 5 PCTs; 1 Acute Trust  
Existing HF services: 1x 0.5WTE HFSN and 1x 0.2WTE HCA  
Geography: City and rural  
HF population: Estimated prevalence HF patients: 9,000 to 13,800 (2.3% population)  
PCT population: Areas of significant deprivation. High black & ethnic minority population in 2 PCTs

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>38</td>
<td>F</td>
<td>July 2004</td>
<td>H</td>
<td>FT</td>
<td>1988</td>
<td>RN ENB 998 Teaching &amp; Assessing ENB 124 Coronary Care BSc Health Care</td>
<td>1 year general acute care 12 years coronary care/ intensive care 2 years cardiology 2 years heart failure specialist nurse (acute)</td>
</tr>
<tr>
<td>18</td>
<td>43</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>PT</td>
<td>1983</td>
<td>RN ENB 998 Teaching &amp; Assessing ENB 124 Coronary Care Diabetes pathway</td>
<td>1 year general acute care 5 years coronary care 2 years research nurse ½ year heart failure nurse (acute) * time for family</td>
</tr>
<tr>
<td>19</td>
<td>29</td>
<td>M</td>
<td>Sept 2004</td>
<td>G</td>
<td>FT</td>
<td>1998</td>
<td>RN ENB R61 Stroke Care ENB 124 Coronary Care Advanced Life Support</td>
<td>2 years general acute (+stroke) care 5 years cardiology</td>
</tr>
<tr>
<td>20</td>
<td>44</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>PT</td>
<td>1983</td>
<td>RN RHV BSc Biology Diploma Adult Education</td>
<td>½ year general acute care 2 years research technician (diabetes) 6 years health visitor (diabetes) 5 years research nurse (cardiology) 8 years antenatal teacher</td>
</tr>
</tbody>
</table>
### Study site 17

**PCTs / Acute Trusts:** 3 PCTs; 1 Acute Trust

**Existing HF services:** 3 BHF HF SNs in the region (1 BHF HF SN currently in one of the PCTs)

2 HFSNs (HAZ funded). BHF funded HFSNs will also cover 2 remaining PCTs not currently covered

**Geography:** City and rural

**HF population:** Estimated prevalence HF patients: 4,752 (2% population)

**PCT population:** High concentration ethnic groups (11%)

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>41</td>
<td>F</td>
<td>Aug 2004</td>
<td>H</td>
<td>FT</td>
<td>1985</td>
<td>SEN RN BSc Advanced Professional Practice ENB 162 Cardiothoracic ENB 249 Cardiothoracic City &amp; Guilds 7307 Teaching Certificate Health Education &amp; Promotion Diploma Management &amp; Supervision</td>
<td>½ year orthopaedics 6 years coronary/ intensive care 12 years cardiology 1 year modern matron cardiology</td>
</tr>
<tr>
<td>2</td>
<td>32</td>
<td>F</td>
<td>Aug 2004</td>
<td>G</td>
<td>FT</td>
<td>1995</td>
<td>RN BA Health Studies</td>
<td>5 years cardiovascular medicine 1 year A&amp;E 4 years medical admissions</td>
</tr>
<tr>
<td>24</td>
<td>32</td>
<td>F</td>
<td>Aug 2004</td>
<td>H</td>
<td>FT</td>
<td>1995</td>
<td>RN BSc Nursing ENB 998 Teaching &amp; Assessing ENB 254 Cardiology</td>
<td>1 ½ years dermatology ½ year cardiothoracic surgery 3 ½ years cardiology/ CCU 2 ½ years CHD clinic (community) 1 ½ years project manager CHD Collaborative</td>
</tr>
</tbody>
</table>
### Study site 11

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>49</td>
<td>37</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>PT</td>
<td>1990</td>
<td>RN ENB 124 Coronary Care ENB 998 Teaching &amp; Assessing ENB 928 Diabetes</td>
<td>3 years acute general medicine 8 years CCU 4 years Diabetes nurse specialist</td>
</tr>
<tr>
<td>50</td>
<td>37</td>
<td>F</td>
<td>Oct 2004</td>
<td>G</td>
<td>FT</td>
<td>1994</td>
<td>RN ENB 998 Teaching &amp; Assessing BSc Clinical Nursing Studies Independent &amp; Supplementary prescribing</td>
<td>11 years acute medicine</td>
</tr>
<tr>
<td>48</td>
<td>44</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>FT</td>
<td>1981</td>
<td>SEN RN ENB 124 Coronary Care BSc Public Health City &amp; Guilds 7307 Teaching</td>
<td>8 years acute general care 7 years CCU 7 years school nurse 1 year conversion * 7 years agency nursing CCU</td>
</tr>
<tr>
<td>81</td>
<td>39</td>
<td>F</td>
<td>Nov 2005</td>
<td>Band 6</td>
<td>PT</td>
<td>1989</td>
<td>SEN RGN ENB 931 Palliative Care Degree modules (Research, ethics, knowledge &amp; practice)</td>
<td>4 years general medicine 10 years palliative care/hospice 3 yrs cardiac rehab</td>
</tr>
</tbody>
</table>

PCTs / Acute Trusts: 1 PCT; 1 Acute Trust

Existing HF services: None. Generic care from district nurses. In Acute Trust - modern matron for cardiology; BHF cardiac liaison nurse

Geography: Geographically large. Rural

HF population: Estimated prevalence HF patients: 2,300 to 3,500 (1-2% population)

PCT population: Areas of low income and poor access to services. Ethnic minority population small
### Study site 15

**PCTs / Acute Trusts:** 3 PCTs; 1 Acute Trust  
**Existing HF services:** 2 HF specialist nurses (hospital/ community). 1 SN (WDC funded 1 year)  
- training, education, support to practices  
**Geography:** Geographically large and remote areas. Rural  
**HF population:** Estimated prevalence HF patients: 4,900 (1-2% population)  
**PCT population:** High numbers of elderly. Ethnic minority population small

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Appointed</th>
<th>Grade</th>
<th>Hours</th>
<th>Qualified</th>
<th>Qualifications</th>
<th>Clinical Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>67</td>
<td>49</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>FT</td>
<td>1988</td>
<td>RN RM Diploma Chronic Disease Management City &amp; Guilds 7307 Teaching</td>
<td>1 ½ years community hospital 7 years midwife (hospital and community) 1 ½ years nursing homes 1 ½ years acute surgery 2 years nurse advisor CHD (pharmaceutical) 3 years practice nurse (GP)</td>
</tr>
<tr>
<td>66</td>
<td>37</td>
<td>M</td>
<td>Jan 2005</td>
<td>H</td>
<td>FT</td>
<td>1995</td>
<td>RN (diploma) Diploma Coronary Care nursing BSc Health Care Studies</td>
<td>1 year respiratory medicine 8 years cardiology/ CCU ½ year heart failure specialist nurse (acute) ½ year heart failure development nurse (comm)</td>
</tr>
<tr>
<td>59</td>
<td>41</td>
<td>F</td>
<td>Sept 2004</td>
<td>G</td>
<td>FT</td>
<td>1986</td>
<td>RN ENB 249 Cardiothoracic City &amp; Guilds 7307 Teaching</td>
<td>1 year paediatrics 8 years intensive care 1 year cardiothoracic ½ year cardiology 4 years agency nursing 1 year sales (wound care products community) 3 years nurse educator</td>
</tr>
</tbody>
</table>
## Style of first interview by site

<table>
<thead>
<tr>
<th>Case site number</th>
<th>HFSN ID</th>
<th>Interview style</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>64, 72, 80</td>
<td>Individual Individual (2006)</td>
</tr>
<tr>
<td>15</td>
<td>58, 65, 66</td>
<td>Individual</td>
</tr>
<tr>
<td>17</td>
<td>1, 2, 24</td>
<td>Group</td>
</tr>
<tr>
<td>22</td>
<td>17, 18, 19, 20</td>
<td>Group</td>
</tr>
<tr>
<td>25</td>
<td>7, 8, 51, 52</td>
<td>Individual</td>
</tr>
<tr>
<td>26</td>
<td>3, 4, 5, 6</td>
<td>Individual</td>
</tr>
</tbody>
</table>
## Appendix 8

### MDT Interview sample

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>BHF nurse lead</td>
<td>22HFSN1</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Assistant Director, Service development</td>
<td>22PCTL2</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Social worker</td>
<td>22SW29</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Palliative care consultant</td>
<td>22PCC34</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Care of elderly consultant</td>
<td>22 CEP38</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Clinical lead Cardiology</td>
<td>22 CLC 39</td>
<td>applicant</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>BHF nurse lead</td>
<td>25HFSN3</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>PCT lead</td>
<td>25PCT17</td>
<td>Not the original applicant</td>
</tr>
<tr>
<td>25</td>
<td>Palliative care nurse manager/ deputy chief Ex of hospice</td>
<td>25PCM25</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>GP</td>
<td>25GP27</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Clinical lead cardiologist</td>
<td>25CLC30</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>BHF nurse lead</td>
<td>17HFSN4</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Nurse operational manager</td>
<td>17PCT10</td>
<td>Not the original applicant but involved in the development of the service</td>
</tr>
<tr>
<td>17</td>
<td>Palliative care consultant</td>
<td>17PCC11</td>
<td>Not funded to support BHF nurses, just personal interest</td>
</tr>
<tr>
<td>17</td>
<td>GP</td>
<td>17GP14</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Clinical lead/ cardiologist</td>
<td>17CL15</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Community matron</td>
<td>17CM16</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>Cardiologist with special interest in hf</td>
<td>17C17</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>GP village</td>
<td>17GP18</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>BHF nurse lead</td>
<td>11HFSN4</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>PCT line manager</td>
<td>11PCT5</td>
<td>New manager is a diabetes specialist</td>
</tr>
<tr>
<td>11</td>
<td>Cardiac rehab nurse</td>
<td>11CRN31</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Cardiac rehab nurse</td>
<td>11CRN32</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Cardiologist</td>
<td>11 CC 40</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Care of elderly consultant</td>
<td>11CEC33</td>
<td></td>
</tr>
</tbody>
</table>
## Models and Appendices

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>BHF nurse lead</td>
<td>15HFSN3</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>PCT/ practice nurse lead</td>
<td>15PCT21</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Care of the elderly consultant</td>
<td>15CEC22</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Cardiologist/ Lead</td>
<td>15CL23</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Palliative care nurse</td>
<td>15PCN24</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>BHF lead</td>
<td>2HFSN16</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Cardiac pathways manager</td>
<td>2PCT12</td>
<td>Original applicant left the organisation</td>
</tr>
<tr>
<td>2</td>
<td>heart failure nurse consultant</td>
<td>2HFNC13</td>
<td>Involved since inception</td>
</tr>
<tr>
<td>2</td>
<td>GP</td>
<td>2GP35</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Social worker</td>
<td>2SW36</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Palliative care nurse</td>
<td>2PCN37</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Site no</th>
<th>Designation</th>
<th>Code</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>26</td>
<td>BHF nurse lead</td>
<td>26HFSN3</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>palliative care consultant (pct based)</td>
<td>26PCC8</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>PCT lead/ community cardiologist</td>
<td>26PCT9</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>cardiologist with special training in hf</td>
<td>26C19</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>District Nurse</td>
<td>26DN20</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>GP</td>
<td>26GP26</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Clinical psychologist/ consultant</td>
<td>26CPC28</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 9

### HFSN Exit Interviews

<table>
<thead>
<tr>
<th>Date</th>
<th>Site</th>
<th>Nurse Id</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>20/06</td>
<td>26</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>21/06/07</td>
<td>25</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>22/06/07</td>
<td>15</td>
<td>66, 67 (opted for a joint session)</td>
<td>59 left in Jan 2006 not replaced.</td>
</tr>
<tr>
<td>27/06</td>
<td>25</td>
<td>52, 8, 51</td>
<td>Individual interviews</td>
</tr>
<tr>
<td>28/06</td>
<td>26</td>
<td>4, 3</td>
<td></td>
</tr>
<tr>
<td>3/07</td>
<td>26</td>
<td>6</td>
<td>Rescheduled - phone interview</td>
</tr>
<tr>
<td>9/07</td>
<td>22</td>
<td>18, 17, 20</td>
<td>Individual interviews</td>
</tr>
<tr>
<td>11/07</td>
<td>17</td>
<td>1, 2 (joint) 24 - left following maternity leave. Interview held in the office shared by community matron who insisted on talking loudly over the phone - not surprisingly, there were issues that could not be probed in her presence.</td>
<td></td>
</tr>
<tr>
<td>19/07</td>
<td>2</td>
<td>72 phone 64 left, 80 left</td>
<td></td>
</tr>
<tr>
<td>24/07</td>
<td>11</td>
<td>48, 49 joint interview (49 returned from sick leave); 50 left Dec.2006</td>
<td></td>
</tr>
<tr>
<td>2/08</td>
<td>11</td>
<td>80 (floods) phone</td>
<td></td>
</tr>
<tr>
<td>27/07</td>
<td>22</td>
<td>80 (floods) phone</td>
<td></td>
</tr>
</tbody>
</table>

Initial interviews: 25  
Interim: 24  
Exit interviews: 20  
(Individual: 12, Joint: 8)
### South Asian patient interview sample

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Gender</th>
<th>Age range</th>
<th>NYHA status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>Male</td>
<td>53 – 69 years</td>
<td>II – IV</td>
</tr>
<tr>
<td>11</td>
<td>8</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Pakistani</td>
<td>Male</td>
<td>49 – 80 years</td>
<td>II – III</td>
</tr>
<tr>
<td>6</td>
<td>5</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total – 17</td>
<td>13</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
### South Asian patient details

#### Table 4 – sample details for South Asian patients

<table>
<thead>
<tr>
<th>Code/area</th>
<th>Ethnicity/gender</th>
<th>Age</th>
<th>Diagnosis and co-morbidities</th>
<th>NYHA status</th>
<th>Carer support</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAP2A</td>
<td>Pakistani Male (did not give permission to record the interview.)</td>
<td>58</td>
<td>IHD, MI, Mod to Severe LVSD, NIDDM. Had 15 HFC visits to titrate meds to this level. Now on 12 monthly follow up with telephone access if required.</td>
<td>NYHA II</td>
<td>Wife sat in, speaks English and actively involved, interviewed in the same session; live in terraced council house</td>
</tr>
<tr>
<td>SAP1A</td>
<td>Pakistani Male</td>
<td>53</td>
<td>NYHA II IHD, MI, Mod LVSD, Hypercholesterolaemia, Hypertension, LVH, LBBB. Had 12 visits HFC and due to attend on 14 Dec 06.</td>
<td>NYHA II</td>
<td>Owns a garage – active – Wife sat in and speaks good English, actively involved, interviewed. Semi-detached house, mixed neighbourhood.</td>
</tr>
<tr>
<td>SAP3A</td>
<td>Pakistani Female</td>
<td>52</td>
<td>NIDDM, Cardiomyopathy, Paroxysmal AF, Echo Mild LVSD. Unable to tolerate further increments in meds due to dizziness. Had 3 visits to HFC. Now on 12 monthly follow up with telephone access if required.</td>
<td>NYHA II</td>
<td>Active and reasonably well, though gets breathless and tired. Daughter and sons help out, husband not much involved/not available for interview. Detached house, middle class neighbourhood.</td>
</tr>
<tr>
<td>SAP4A</td>
<td>Indian Sikh Male</td>
<td>59</td>
<td>Atrial Flutter, LVH, Mod LVSD, Very severe RVSD, Chronic Renal Failure, MI, IDDM. Titration has been unpredictable since he has been out of the country during summer. Has attended 5 HFC visits, DNA 2 appointments, received 2 home visits and been seen as an in-patient. He is due to be seen in HFC with an interpreter to address wife’s request (following my feedback).</td>
<td>NYHA III</td>
<td>Sons live locally, wife sat in and said that she would have liked more information about husband’s illness, especially since she can’t speak or read English. Feedback to HFSN and a visit with an interpreter arranged. Terraced House.</td>
</tr>
<tr>
<td>Code/area</td>
<td>Ethnicity/ gender</td>
<td>Age</td>
<td>Diagnosis and co-morbidities</td>
<td>NYHA status</td>
<td>Carer support</td>
</tr>
<tr>
<td>-----------</td>
<td>------------------</td>
<td>-----</td>
<td>------------------------------</td>
<td>------------</td>
<td>---------------</td>
</tr>
<tr>
<td>SAP6B</td>
<td>Indian – Hindu Male</td>
<td>53 years</td>
<td>Dilated Cardiomyopathy, Aortic and Mitral valve replacement 2003. Awaiting bi-vent/ICD insertion, Echo dilated cardiomyopathy, MIBI abnormal perfusion EF13%.</td>
<td>NYHA II</td>
<td>Works shifts as a security guard, lives in a council flat, with partner following divorce. Partner has not had any contact with the HFSN. Live in a council one bedroom flat, damp and close to the estate bins.</td>
</tr>
<tr>
<td>SAP5B</td>
<td>Indian Hindu Female</td>
<td>67 years</td>
<td>IHD – MI 1999, 2000 Failed PCI 2000, Type II Diabetes CVA, LVSA, Palliative approach, few months back was very terminal but she seems to have decided to bounce back. MIBI report: severe ischaemic cardiomyopathy.</td>
<td>NYHA III-IV</td>
<td>Daughter-in-law main carer – severely restricted – bed bound, had a stroke – on oxygen – day time nursing care. No bath or toilet downstairs. Detached house, nephew and wife visiting from India, 2 other sons live locally.</td>
</tr>
<tr>
<td>SAP7B</td>
<td>Indian – Hindu Male</td>
<td>Dilated Cardiomyopathy Hypercholesterolemia Past craniotomy – evacuation of haematoma, CVA, Epilepsy.</td>
<td>NYHA II</td>
<td>Wife quite vocal and did most of the talking – new referral not much experience. Issues with GP. Son lives locally.</td>
<td></td>
</tr>
<tr>
<td>SAP8D</td>
<td>Pakistani Male</td>
<td>80 years</td>
<td>Hypertension, diabetes.</td>
<td>NYHA III</td>
<td>Quite restricted and breathless – wife had gone out shopping and could not be interviewed. Semi-detached house.</td>
</tr>
<tr>
<td>SAP9D</td>
<td>Pakistani Male</td>
<td>49 years</td>
<td>Rheumatic mitral valve disease, mitral valve replaced; atrial fibrillation, previous stroke; Beta thalassaemia trait.</td>
<td>NYHA II</td>
<td>Council, terraced house – 7 children – wife sat in and interviewed in the same session.</td>
</tr>
<tr>
<td>SAP10D</td>
<td>Indian – Hindu/ Sikh Male</td>
<td>64 years</td>
<td>Hypertension, constrictive pericarditis, TB lymph nodes.</td>
<td>NYHA II</td>
<td>Live in a middle class suburb, professional background, still very active, wife interviewed and keen on a healthy lifestyle and exercise.</td>
</tr>
<tr>
<td>SAP11D</td>
<td>Indian – Sikh Male</td>
<td>60 years</td>
<td>Hypertension.</td>
<td>NYHA II</td>
<td>Lives in a council house, own a shop and lives with 2 sons, wife busy with the shop. Wife does not have much contact with HFSN. New referral.</td>
</tr>
<tr>
<td>Code/area</td>
<td>Ethnicity/ gender</td>
<td>Age</td>
<td>Diagnosis and co-morbidities</td>
<td>NYHA status</td>
<td>Carer support</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------------</td>
<td>-----</td>
<td>----------------------------</td>
<td>-------------</td>
<td>---------------</td>
</tr>
<tr>
<td>SAP12D</td>
<td>Indian – Sikh</td>
<td>69</td>
<td></td>
<td></td>
<td>Live in a council, terraced house with bathroom and toilet upstairs – has a shower only once a week. Daughter-in-law, main carer interviewed in the same session. Husband alcohol problem.</td>
</tr>
<tr>
<td>SAP13C</td>
<td>Indian – Sikh</td>
<td>66</td>
<td>Co-Morbidities: Mild LVSD, Ischaemic HF, High Cholesterol. Visits: 1 Home visit (2006) Telephone call (2006) Medication as at 2006 – Omeprazole 20mg, Nicorandil 20mg, Isosorbide Mononitrate 60mg, Simvastatin 40mg, Atenolol 75mg, Perindopril 4mg, Furosemide 80mg, Clopidogrel 75mg, Aspirin 75mg.</td>
<td>NYHA II</td>
<td>Can’t read or write. Lives with her husband, son, daughter-in-law and grandson in a suburban middle class neighbourhood. Heart problem not a major worry – can walk on level, and do some kitchen work, main worry is son who has a brain tumour, in the hospital. Grandson also has a brain tumour and not able to talk. Could not remember seeing an Asian heart nurse either after surgery or recently – nor could the daughter-in-law. The (DN) nurse visited her to dress her wound after surgery. Reasonably well at present.</td>
</tr>
<tr>
<td>SAP14C</td>
<td>(Gujarati – Hindu, moved from East Africa and speaks fluent Punjabi)</td>
<td>55</td>
<td>Co-Morbidities: Moderate LVSD, Ischaemic HF, Diabetes on Insulin. Visits: - Had quite a few contacts in the past 3 years, however over the past year: 2 home visits (2007) 1 telephone call (2007) 3 other visits (OPD, 2007) Medication: - Nicorandil 10mg, Simvastatin 40mg, Aspirin 75mg, Metolazone 2.5mg, Furosemide 80mg and 120mg, Lisinopril 20mg, Eplerenone 25mg, Imdur 90mg, Carvedilol 25mg bd.</td>
<td>NYHA III</td>
<td>Quite severely restricted by his heart condition. Lives with wife and son in a mixed neighbourhood – terraced house, off licence shop, run solely by wife. Speaks good English – in contact with the HFSN and finds her support useful. Wife works at the shop – busy.</td>
</tr>
<tr>
<td>Code/area</td>
<td>Ethnicity/ gender</td>
<td>Age</td>
<td>Diagnosis and co-morbidities</td>
<td>NYHA status</td>
<td>Carer support</td>
</tr>
<tr>
<td>-----------</td>
<td>------------------</td>
<td>-----</td>
<td>-----------------------------</td>
<td>-------------</td>
<td>---------------</td>
</tr>
</tbody>
</table>
| SAP15C    | Pakistani Muslim – Punjabi speaking, can’t read English | 52 years | Class 11  
Co-Morbidities:  
Hyperthyroidism, Thyrotoxicosis, AF.  
Visits: 1 Home visit (2005)  
Telephone calls – 2 (2005)  
Clinic visit – 1 (2005) | NYHA II | Lives in a suburb, detached house with wife and 2 sons, youngest A level.  
Wife works in town – walks to work. English an issue.  
Had seen the link nurse – who visited home.  
Major concern – sexual dysfunction – discussed it with his doctor.  
Wife interviewed. |
| SAP16C    | Indian-Sikh      | 62 years | NYHA status –  
Co-Morbidities: Mild LVSD, Ischaemic HF, Know IHD, High Cholesterol.  
Medication as at 2006 – Clopidogrel 75mg, Candesartan 4mg, Bisoprolol 1.25mg. | NYHA II | Quite well and active  
– Speaks good English.  
Lives in a middle class suburb – detached, very well furnished house.  
2 children at University – responsibilities. Wife works.  
Not available for interview.  
Main theme – racism  
– from observation rather than personal experience.  
He seems to have been fending for information in the library and clinics – did not seem to have a booklet. |
| SAP17C    | Indian Sikh      | 55 years | Co-Morbidities: Severe LVSD, Ischaemic HF, Known IHD, High BP, High Cholesterol, Diabetes, Valve Disease.  
Visits:  
1 Home visit (2005)  
4 Clinic visits (2005)  
2 Telephone contacts (2005).  
Medication as at 2005 –  
Atorvastatin 20 mg, Amiodarone 200mg, Losartan 50mg, Spironolactone 25mg, Furosemide 40mg, Aspirin 75mg, Bisoprolol 5mg. | NYHA III | Lives with wife and 2 children at university, can’t go out on his own, no licence, stopped working, waiting for a treatment plan, religious issues  
– believes covert racism could be responsible for delay. See an Asian face – assume can’t speak English  
– works in subtle ways  
– don’t show it though.  
Wife interviewed. |
Appendix 12

Nurse exit interviews topic guide

Topic guide for exit interviews

Protocols for admission, caseload management and discharge
- Physical location and changes within team
- Average pattern of referrals – change since interim interview
- Average caseload – change since interim interview – ideal case load
- Taking care of patients within community
- Protocol for discharge

Access to services for patients, supporting carers and issues of equity
- Access to other services across primary and secondary care
- Current gaps
- Are these services suitable for all – age, gender and ethnicity
- Support for carers
- Changes since interim interview

Working within a multi-disciplinary framework
- Links with other teams and professionals – strong and weak links
- Knowledge and transfer of skills
- Links with palliative care
- Maintaining boundaries – negotiating with community matron and role of complex and chronic disease management experts
- Changes since interim interview

Reconfiguring of PCTS, other changes and future
- Impact of reconfiguration of PCTS
- Managing more complex cases, providing specialised or generic care for the heart failure patients
- Future of the role of the heart failure nurse specialist and the service
Appendix 13

MDT topic guide

Topic guide
MDT professional interviews

How do you place yourself within the multidisciplinary team taking care of patients with heart failure?

Network between primary, secondary and voluntary sectors – strong links and weak links.

What is your role in supporting the British heart Foundation (BHF) specialist heart failure nurse?

How has the multi-disciplinary approach improved care of the patients with heart failure?

How has the HFSN been involved in supporting you in taking care of patients with heart failure?

Do you think this support has improved the care you have been providing to these patients?

If yes/no, in what ways?

Have you been involved in any formal/ informal way of supporting or training the HFSN to care for their patients?

What skills and knowledge have you passed on to the HFSN?

Are there any gaps in the current service within your patch that you would like to be addressed?

How good are the services for patients and carers from minority ethnic backgrounds within your area?

How do you envisage the future of the service?

Appendix 14

PCT lead guide

1. Remit
2. Existing service and gaps
3. Multi-disciplinary team and links
4. Ethnic minority patients and their needs
5. PCT reconfiguration and potential impact on BHF HFSN’s future
Appendix 15

Topic guide for carers

Topic guide for use with interviews of non-English speaking carers

The interviews are semi-structured to ensure that the interview covers issues of importance to the carer. This outline is to be used as a general guide.

Caring responsibilities

What are your main caring responsibilities for your relative with heart failure?

A. Physical – meals, intimate care (washing/dressing/toileting), walking & transfers.
B. Treatments – medications, contacting GP/nurse, assessing treatments, comfort.
C. Help the relative manage their illness better – weighing – diet-fluid intake exercise
D. Who else helps with these matters? Adult children at home, living close by?

Effects of caring

Do you feel responsible for your relative’s well-being?
Do you feel able to go out or to be with them 24 hours a day?
Do you get a rest from caring during the day?
Are you disturbed during the night because your relative needs help/care?
Has caring for your relative limited your social activities or your ability to work?
Has caring altered your relationship with your relative?

Health and well-being

How would you say your general health is?
Have you been feeling downhearted or depressed recently? Is this related to caring for your relative with heart failure?
Have you been feeling anxious recently? Is this related to caring for your relative with heart failure?

Satisfaction with specialist nurse service

Are you satisfied with the specialist nurse service and care provided to (a) your relative (b) you as main carer?
Do you feel you get enough information about your relative’s treatment and care?
Who provides this information to you? Is it mainly the specialist nurse? Is it mainly an interpreter? Or, is it another health care professional?
In what ways has the specialist nurse service been useful?
Are there things that you would like the specialist nurse to do that he/she currently does not do?

Is there anything else you would like to tell me about caring for your relative with heart failure or the specialist nurse service?

Explain how data is being used
Reiterate about anonymity/confidentiality
Thank you
Appendix 16

Topic guide for use with interviews of non-English speaking patients

The interviews are semi-structured to ensure that the interview covers issues of importance to the patient. This outline is to be used as a general guide.

Health and well-being

How would you say your health has been a) over the past 6 months b) the past year?
How are your heart failure symptoms at the moment (breathing, fatigue, weight, swelling, dizziness, sleeping)?
How do you manage your symptoms (weighing self, diet, physical activity, medications, alcohol, smoking, appointments with GP/nurse)?
Have you been feeling downhearted or depressed recently? Is this related to heart failure diagnosis?
Have you been feeling anxious recently? Is this related to your heart failure diagnosis?

Levels of physical activity

Does your heart failure limit you in your day-to-day activities (such as washing and dressing/ cooking)?
Does your heart failure limit you in your social activities (such as visiting friends/ relatives, going to the mosque/ temple)?

Satisfaction with specialist nurse service

Are you seeing a heart failure nurse at the moment?
How long have you known this nurse and how did you get to know her/him?
What are the kinds of things this nurse helps you with?
Do you feel you get enough information about your treatment and care?
Who provides this information to you? Is it mainly the specialist nurse? Is it mainly an interpreter? Or, is it another health care professional?
In what ways has the specialist nurse service been useful?
Are you satisfied with the specialist nurse service?
Are there things that you would like the specialist nurse to do that he/ she currently does not do?
Is there anything else you would like to tell me about your heart failure or the specialist nurse service?

Explain how data is being used
Reiterate about anonymity/ confidentiality
Thank you
Heart failure is common, costly, and impacts greatly on quality of life. HFSNs can reduce hospital admissions and improve outcomes, resulting in reduced costs and better care for patients.

HFSNs can improve health-related quality of life in both hospitals and the community.

HFSNs can help patients understand and manage their condition, providing them with education and advice about heart failure, its treatment, and what to do if they have a problem. They have a key role in enabling patients and carers to navigate the patient pathway.

HFSNs can help to educate, support, and manage stable patients, including monitoring and adjusting medication (QOF) targets by organizing carefully planned and controlled heart failure reviews.

HFSNs can co-ordinate a shared care approach to end of life care, working with the hospital-based and community HFSNs and the multi-professional team. These staff would develop a care plan for inpatients and then discharge to the community HFSNs for follow-up care.

HFSNs can help to keep stable patients out of hospital, perform a regular review of patients with advanced heart failure, and provide education, support, and management of symptoms and co-morbidities.

Heart failure specialist nurse (HFSN):

1. Clinical and management leadership and involvement are crucial for clinical and secondary care. A multi-professional steering group is essential for developing agreed referral protocols and patient pathways. These should include evidence-based drug therapy, together with applications with ‘Help of Heart Services’ and clarifying the框架 to avoid inappropriate referrals.

2. Education and training should be provided for all staff involved in the management of stable patients, and at least some of HFSNs should be involved. This is a safe number to have when doing home visits. Nurse-led services can be recommended. Nurses report that an active caseload of 50 is a safe number to have when doing home visits. Nurse-led care reduces hospital visits.

3. There must be good communication between the HFSNs and other staff and external services in the community and secondary care. There must be regular reinforcement of self-care strategies and monitoring of stable patients. A patient pathway should be tailor-made to meet the specific needs of particular health-care environments and patients.

4. The use of interactive methods to monitor patients should be considered. There needs to be access for both stable and unstable patients to the service. A patient pathway should be tailored to meet the specific needs of particular health-care environments and patients.

5. There are core elements that need to be considered when developing a pathway for patients. The framework (QOF) targets by organizing carefully planned and controlled heart failure reviews.

6. There needs to be a pathway in place to enable patients to have a coordinated approach if they remain symptomatic, in order to reduce the risk of re-admission and do so if they have a problem. They have a key role in enabling patients and carers to navigate the patient pathway.

7. There needs to be a pathway in place to enable patients to have a coordinated approach if they remain symptomatic, in order to reduce the risk of re-admission and do so if they have a problem. They have a key role in enabling patients and carers to navigate the patient pathway.

8. There are core elements that need to be considered when developing a pathway for patients. The framework (QOF) targets by organizing carefully planned and controlled heart failure reviews.

9. There are core elements that need to be considered when developing a pathway for patients. The framework (QOF) targets by organizing carefully planned and controlled heart failure reviews.

10. There are core elements that need to be considered when developing a pathway for patients. The framework (QOF) targets by organizing carefully planned and controlled heart failure reviews.

The Development and Impact of the British Heart Foundation and Big Lottery Fund Heart Failure Specialist Nurse Services in England

Final Report April 2008

Jill Pattenden
Simon Coulton
Karen Spilsbury
Sanjogeta Chattoo
Bren Cross
Val Wadsworth
Bob Levin

Funded by