

# **THE BRITISH HEART FOUNDATION HEART FAILURE SPECIALIST NURSE**

## **EVALUATION OF A NEW SERVICE**

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**Ms. J. F. Pattenden BA (Hons), MSc, PGCE  
Prof. R. J. P. Lewin MA (Hons), Mphil  
Ms H. Roberts MSC, PGDipEd, RN  
Dr J.N.V. Miles BA (Hons), PhD  
British Heart Foundation Care and Education Research Group  
Dept of Health Sciences  
University of York  
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# THE BRITISH HEART FOUNDATION (BHF) HEART FAILURE SPECIALIST NURSE

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If you wish to know more, or to comment on this report, please contact Ms Jill Pattenden at the BHF Care and Education Research Group, Seebohm Rowntree Building , University of York, YO10 5DD. 01904 321335 [JP30@york.ac.uk](mailto:JP30@york.ac.uk).

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## 1. The background

Heart failure is an increasingly common condition with a prevalence of around 2% in most developed countries.<sup>1</sup> In the UK there are approximately 878,000 people living with heart failure. Heart failure is associated with a poor prognosis and living with heart failure is often frightening, restrictive and distressing for patients and their carers. Patients are frequently admitted to hospital, 5% of all hospital admissions are due to heart failure, and up to 50% of heart failure patients are readmitted to hospital within 3 months of discharge.<sup>2</sup> Heart failure is strongly associated with ageing, co-morbidity and deprivation and the high rates of co-morbidities, and prevalence rates, have important implications for delivering medical services.<sup>3 4</sup> Nurse-led care, in which a specialist nurse co-ordinates care, may offer a solution and the SIGN guidelines have suggested that the role of the heart failure specialist nurses is of particular interest.<sup>5</sup> However, it is not clear how best to organise nurse-led services.

A systematic review of randomised trials of disease management programmes in heart failure concluded that programmes that involve patient education and specialised follow-up by a multidisciplinary team improve prescribing practices, reduce hospitalisations and appear to be cost saving. It found a lack of evidence for an effect on survival.<sup>6</sup> Several recent studies have shown benefit from nurse-led programmes for patients with heart failure, including a reduction in hospital readmissions and prolonging event-free survival<sup>7</sup>. A few studies have shown an improvement in quality of life.<sup>8</sup> A recent review of nurse-led interventions led Stewart to conclude that programmes which focus on 'high risk' older, fragile patients are cost effective.<sup>9</sup> In recognition of the burden heart failure places on patients and the evidence that specialist nurses can improve patient outcomes, the BHF funded a pilot scheme to establish 16 heart failure specialist nursing posts across the UK. The aim of the scheme was to improve the treatment of heart failure and quality of life for patients and carers.

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## 2. Overview of the evaluation

### 2.1 Aims

The study

1. examined the *impact* that introducing the nurses had on the health and well being of patients and their carers viewed from the patients' perspective. This part of the evaluation took the form of a questionnaire based survey conducted before and after the nurse intervention and semi-structured interviews with a sample of the patients to discover the needs they had and how they perceived the help the nurses gave them. At the suggestion of the research steering group, for a year, we also looked at the use of medication, the number of readmissions to hospital and mortality.
2. examined the *processes* involved in service implementation, to formulate recommendations as to the future development of the service. This took the form of diaries kept by the nurses in which they noted the barriers and facilitating factors in developing their practice and exit interviews with the nurses examining some of the themes that arose from these diaries.
3. combined the two views, that of the patients and of the nurses, to make a number of *recommendations* to guide the development of the BHF Specialist Heart Failure Nurse Service.

This report is structured

1. firstly to describe the *methodology*
2. secondly, reporting on the *impact* evaluation
3. in the third part examining the *processes* that shaped the service
4. finally synthesising the findings into a series of *recommendations*.

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## 3. Methods

Because our aims included both a *process* evaluation and an *impact* evaluation the method chosen was a 'developmental evaluation'. This pays particular attention to the subjective experience and views of patients and the health personnel who are affected by the innovation.<sup>10</sup> Studies of this kind can help clinicians to better understand the process of implementing a new service including what can go wrong and what the unexpected effects might be when the new service is rolled out to a larger population.<sup>11</sup> This method can be both motivational and educational as those involved receive feedback from their client group.<sup>12</sup>

### 3.1 The setting

The BHF scheme funded 16 nurses at 6 centres: a central city teaching hospital, 3 urban hospitals and 2 rural hospitals. The teaching hospital was excluded from the study due to the length of time taken to recruit staff. The evaluation involved 14 nurses in 5 centres.

### 3.2 The patients

Patients were identified by the nurses from outpatient clinic lists or referred to the service from: cardiology, general medical or care of the elderly wards.

**3.2.1** The inclusion criteria were: patients with a diagnosis of heart failure (Left Ventricular Systolic Dysfunction) referred to the BHF nurse and who had not previously been seen by a heart failure specialist nurse.

The exclusion criteria were: patients who had a written case record of cognitive deficits; were unable to make daily decisions about their own care; were living in residential care or were unwilling to accept the specialist nurse service.

**3.2.2** Recruitment and consent. The specialist nurses were asked to give an information sheet to all eligible patients inviting them to participate in the study. Written informed consent was obtained from each patient and carer prior to completing questionnaires or being interviewed.

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For those choosing not to be 'enrolled' in the full study, anonymised data were collected on gender, age, NYHA class and co-morbidities.

Several factors influenced enrolment, the most influential were the severity of patient illness, the staffing situation in each centre and the individual nurse's ability or willingness to recruit to the study. The recruitment rate to the full study in each centre is shown in Table 1.

**Table 1 - Numbers of patients, enrolled and not enrolled in the study by centre.**

CENTRE	NO. NURSES	ENROLLED	NOT ENROLLED	TOTAL
Bradford	3	54	131	185
Dumfries	2	71	28	99
Birmingham	4	83	279	362
Causeway	2	39	26	65
Leicester	3	54	158	212
Total	14	300	623	923

**3.2.3** By October 2003 the nurses had seen 923 patients, including 676 for whom basic socio-demographic data were available. The ratio of males to female patients was 2:1; 90% of patients were classified as white, 3% as Afro-Caribbean and 7% as South Asian; 57% of patients were married or living with a partner, 29% lived alone and data were not provided for the remaining 14%. Ages ranged from 25 to 95 with a median age of 74; 7% of patients were classified as NYHA Class I, 39% as Class II, 37% as Class III and 17% as Class IV. NYHA Class I implies no limitations in physical activity; Class II implies slight limitation of physical activity; Class III implies marked limitations of physical activity; and Class IV implies unable to carry out any physical activity without discomfort. A series of tables summarising the activity in the five centres are presented in the appendices.

# THE IMPACT STUDY

## CARER

“One of the best things she suggested was that [name] weigh himself every day. Nobody suggested that before at all. ....if it goes up a couple of kilograms you’re getting fluid retention..... it used to build up and build up ...he knows, you know, right away and then we phone [Nurse] and she alters...tells him the drugs to take, the diuretics. It is good because it stops him ending back up in hospital.” (cr 3)

## PATIENT

“Well that gives you the confidence to be able to deal yourself with the illness really.” (pt 3)

## PATIENT

“The reassurance that there is someone you can speak to that there is someone there at the end of a phone, not necessarily to get him out, but someone at the end of the phone saying I’ve got these symptoms what do you think.” (pt 25)

## PATIENT

“.....She’s our sort of link between the doctor, well both the GP and the specialist and us, and she’ll do the leg work and telephone around because she knows who people are and she’ll get things done.” (pt 7)

## CARER

“We started the journey together and ended it together.” (carer supported by nurse 7)

## PATIENT

“I never used to [cook], I was feeling dizzy and before I couldn’t cook for anyone now I can cook for 15 people...” (pt 26)

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## 4 The impact evaluation

### 4.1 Methods

**4.1.1** Questionnaires. Patients were asked to complete 4 questionnaires on 2 occasions: at the start of the nurse intervention and 3 months after the first contact.

These included the:

- SF36, a generic health related quality of life questionnaire
- Minnesota Living with Heart Failure questionnaire (MLHF)
- Hospital Anxiety and Depression questionnaire (HAD)
- Brief Leisure Time Exercise questionnaire (BLT)

Patients posted these to the research secretary in York who scored them and entered them into a database. Analysis was carried out by a medical statistician at York.

**4.1.2** Interviews. The qualitative approach used was that recommended by Strauss and Corbin.<sup>13</sup> We employed purposive sampling, guided by a review of the literature, to ensure the inclusion of patients with relevant features in their presentation. The 4 categories used in the sampling strategy were:

- gender
- age
- ethnic group
- NYHA classification of severity of heart failure

The patients who had been selected were contacted by telephone and an appointment arranged. A subset of patients received a second interview 5 months after the initial interview. The semi-structured interview explored:

- the patient's understanding of their condition
- their perceptions of the difficulties and management of their illness
- their previous experience of services for heart failure
- whether the specialist nurse service was having an impact on their physical, social and emotional health and well-being
- any gaps in service provision and if there were ways in which the service could be made more effective for them

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- carers were also asked to give their views on the service and whether it had improved care on issues important to them and the patient

Interviews took place at a time and place chosen by the respondent, most frequently in their own home. All were audio-taped and transcribed verbatim. At the second interview, summarised transcripts of the first interview were read to the patients for confirmation of accuracy. Field notes were made by the interviewer, during and after the interview and added to the transcription as addenda. A trained bilingual research nurse in Bradford conducted interviews in Punjabi or Urdu where necessary, and a Gujarati speaking interpreter was used for one patient in Leicester.

**4.1.3** Analysis of interviews. The transcripts were read by the lead researcher, and emergent themes were discussed with the team. The interviews were then coded line-by-line to enable identification of areas which could be grouped together as themes using the NVivo computer package. To check reliability of coding two members of the research team independently examined 20% of the coded data and compared interpretations. The final analytical concepts were agreed with the research advisory group which included a patient with heart failure, his main carer and nurses responsible for the management of patients with heart failure.

**4.1.4** Medications, readmissions and mortality. We had not originally intended to collect audit data, however, once the study was underway the research advisory group asked if it would be possible to gain some insight into the uptake of medication, readmission rates and mortality. At our request, nurses sent retrospective information covering the missing period (October 2002 to April 2003) and thereafter reported readmissions and deaths as they occurred. Medication rates were obtained from records made at first contact with the specialist nurse, usually on discharge from hospital or at the first clinic visit following discharge.

### **4.2 Findings from questionnaires**

In reading this section it is important to remember that this was not a randomised trial with a control group. The questionnaire scores provide a picture of the health and quality of the patients' lives. They also show us how things changed over five

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months, but from this we can draw no firm conclusions as we do not know how patients would have scored had they not seen a nurse.

**4.2.1** Patients were consented for this part of the study and many felt too unwell, were in other clinical trials, or their nurse felt reluctant to ask them to take part in the study whilst they were recovering from an acute phase of the illness. As a result fewer NYHA class 4 patients entered the study. Of the 676 patients in the nurses' caseloads, 300 (44%) took part in the questionnaire study and returned completed questionnaires at Time 1, and 202 (30%) completed them at Time 1 and Time 2. NYHA classification was the only significant predictor of participation, with only 21% of those in NYHA class 4 responding.

Statistical analysis was carried out using SPSS 12.0. Analysis of change was carried out using Wilcoxon tests for the MLHF and the BLT and paired Student t-tests were used for the SF36 and the HAD.

**4.2.2** Anxiety and Depression. At Time 1 approximately 50% of patients scored above the level that indicates a person might benefit from treatment. This was the case for both anxiety and depression. There was no significant change in these scores at Time 2. However it may be that the HAD is not an appropriate measure for this group of patients, as several reported that 2 of the depression items reflected their inability to do their usual pleasurable activities, which was in fact due to heart failure not depression per se.

**4.2.3** Quality of life: SF36. Mean scores at baseline on the SF36 revealed these patients to have a worse quality of life than patients normally enrolled in randomised trials of specialist nurse interventions or drug trials and slightly worse than those reported from a large cross-sectional survey of heart failure patients living in Birmingham.<sup>1</sup>

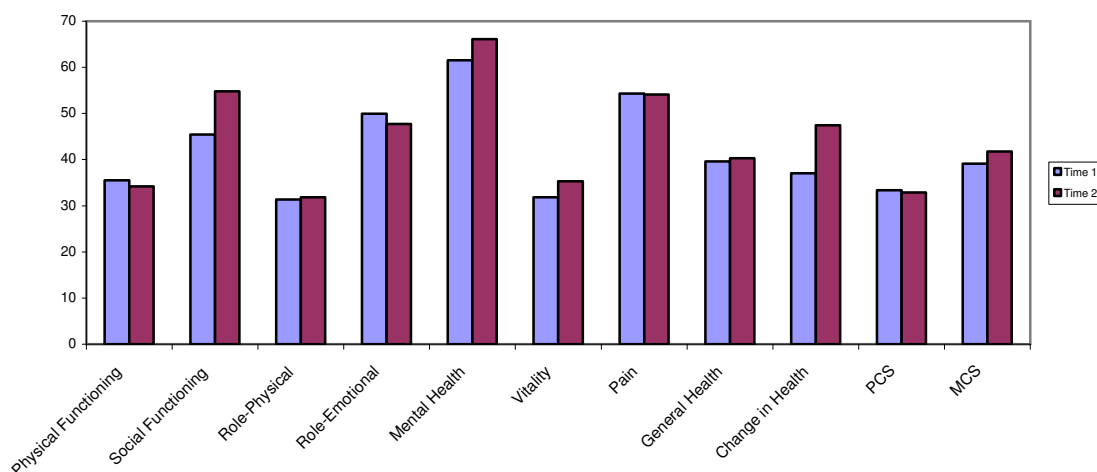
At follow up patients showed significant improvement in two SF36 subscales, 'social functioning' and 'perceived change in health', and significant deterioration in the 'role-emotional' subscale (Table 2, Fig 1).

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Table 2: SF36 scores at Time 1 & Time 2

	Time 1		Time 2		Sig. P =
	Mean	Std. Deviation	Mean	Std. Deviation	
Physical Functioning	35.5	28.4	34.2	27.0	0.1
Social Functioning	45.4	33.6	54.8	31.1	0.005
Role-Physical	31.4	29.8	31.9	26.2	0.77
Role-Emotional	49.9	33.6	47.7	33.0	0.01
Mental Health	61.5	22.9	66.1	21.8	0.06
Vitality	31.8	22.9	35.3	21.8	0.19
Pain	54.3	30.3	54.1	28.5	0.86
General Health	39.6	22.6	40.3	21.3	0.29
Change in Health	37.1	29.1	47.5	27.5	0.001
Physical component summary (PCS)	33.4	10.8	32.9	9.9	0.21
Mental component summary (MCS)	39.2	13.8	41.8	12.9	0.65

Figure 1. Mean scores on the SF36 dimensions at Time 1 & Time 2



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**4.2.4** Quality of life: Minnesota Living With Heart Failure (MLHF). The mean score at baseline for the MLHF was 49 (range 0 – 105). A lower score implies better health. There was a significant change in a positive direction with a larger number of people improving their score than remaining the same or getting worse. (Table 3) The largest improvement in MLHF scores occurred in those with most severe heart failure, NYHA class 4, with a mean reduction of approximately 10 points. A change of 5 points is regarded as being clinically significant.

**Table 3: Changes in MLHF score from Time 1 to Time 2**

	Direction of change	N =
MLHF Total	Down	99
	Up	85
	Ties	4
	Total	188
	P	0.05

**Table 4: Mean change in MLHF score by NYHA**

NYHA class	Mean (SD)	No. of Pts (%)
1	1.5 (11)	15 (8.3%)
2	-1.9 (20)	94 (52.2)
3	-8.3 (22)	58 (32.2%)
4	-10.6 (22)	13 (7.3%)
Total	-4.3	

**4.2.5** Physical Activity. The median activity score was 12, which equates to 4 sessions of 15 minutes of mild activity per week; this was mostly in patients who were NYHA class I. Only a few patients reported any activity at the moderate level and a large number of people, particularly those in NYHA class III and IV, were doing nothing. This did not change significantly at follow up.

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## 4.3 Findings from interviews

**4.3.1 Patient characteristics.** In order to obtain maximum representation of heart failure patients we selected 7-8 from each centre, a total of 36 patients and 20 carers were interviewed. Of those 23 male patients and 13 female patients interviewed, 3 (9%) were classified as having heart failure NYHA Class I, 12 (33%) as Class II, 13 (36%) as Class III and 8 (22%) as Class IV, of whom 29 were white, 2 Afro-Caribbean and 5 were of Asian origin. After 5 months 16 patients and 6 carers were interviewed again. Patients who gave a second interview were those who remained well enough, had been in contact with the specialist nurse since the first interview, and felt they had further comments to make.

Although the interviewer asked to see the patient and carer separately, most expressed a wish to be interviewed together. In those cases, attempts were made to have a few minutes alone with each, to give them a chance to disclose information they would not talk about in front of their partner.

**4.3.2 The impact of the condition : the seven themes.** All participants identified a number of areas of concern. Many of these concerns were also highlighted in the nurse field notes as those most often mentioned by patients. There were six major themes and one specific to Asian patients (7):

- 1) Symptoms
- 2) Multiple medications
- 3) Co-morbidities
- 4) Adapting life to heart failure
- 5) Psychological effects
- 6) Carer Issues
- 7) Cultural and language difficulties

### **1-3) Symptoms, multiple medications and co-morbidities**

The first three themes overlapped considerably and are presented here together. Managing symptoms such as tiredness, breathlessness and ankle swelling, balancing medications against their side effects and coping with painful and disabling co-morbidities made life extremely difficult for many patients. Many patients and carers

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valued the role of the specialist nurse in helping them self-manage their diuretics. They felt they had become more knowledgeable about their drugs and reported increasing confidence in managing tablets. The extent to which symptoms impacted on life depended both on the severity of the heart failure and the persons coping style.

Co-morbidities such as diabetes, chronic obstructive pulmonary disease, angina, arthritis, gout and kidney problems were particularly common. Some people found them more of a problem to live with than their heart failure.

Some patients felt “shattered” after the slightest effort and said how breathlessness significantly affected their ability to undertake daily activities. Other patients experienced nocturnal breathlessness. This was frightening, affected their ability to sleep and exacerbated other symptoms, especially fatigue and anxiety.

As the medical management of the heart failure symptoms improved, the side effects and co-morbidities often increased. Several patients expressed a fear that some medications were doing more harm than good, making them feel worse and causing side effects such as gastric disturbances. For some it was the volume of drugs they had to take that proved difficult.

Many patients said how bad their memories had become since they developed heart failure. As a result some had become anxious about managing their complex drug regimens, keeping all of the hospital appointments and remembering the lifestyle advice they had been given.

Many patients mentioned the unpredictability of symptoms, this caused great distress to both patients and carers who felt they didn't always understand why things weren't improving or suddenly got worse.

### **4) Adapting life to heart failure**

It was clear that heart failure had a significant impact on the lives of the patients and their carers. Many patients experienced frustration at no longer being able to do what they used to do. It was apparent that some patients had voluntarily limited their

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activity levels due to a fear that activity would exacerbate their symptoms and lead to a hospital admission.

Three patients mentioned positive outcomes to their quality of life. All were under 60 years of age and had given up full time employment as a result of their heart failure. They saw their illness as an opportunity to change certain aspects of their lives such as pursuing further education or taking up a different activity.

Where an inability to continue working was mentioned, worries about finances were also raised. Poverty often compounded a patient's ability to manage to live a normal life, especially if they needed to have adaptations to their home. Difficulties in accessing benefits such as income support, disability allowance or social services assessments caused great distress for some. The problems were greatly increased for those who did not speak English. As one Asian man said:

“when I wash my feet I lift my legs up to the basin...and it's so painful. ....If I had the money I'd have a basin installed lower down, this one's too high...he [the NHS interpreter] said that this money is not right, you are 100 per cent disabled and should get disability allowance. I thought, who do I have that can go there and fill out the forms... my wife can't either” (pt 33).

Patients often became irritable, blaming feelings of guilt at being unable to help with household chores, becoming dependent on others and the loss of pleasurable activities. Changes in the patients role within the family and a loss of social relationships were common problems. Some patients and their carers had become virtually housebound.

“We were due at a party the other week, weren't we, in Halifax at my niece's and I couldn't go because there's stairs and things and it's quite easy to lose touch with civilisation really” (pt 2).

### 5) Psychological effects

Whilst some patients were frightened and others depressed some, particularly the older women, talked quite philosophically about the future:

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“The condition’s there, and they can’t cure it so trying to accept it, this is the big thing” (pt 16).

Some patients reported anxiety that could last for weeks after an acute episode, some found themselves unable to forget the event. Two patients who had experienced frightening acute events were told there was no guarantee that they wouldn’t have another. They reported being terrified of going to sleep. Some patients reported having bad nightmares and anxiety attacks whilst increasing the dose of beta-blockers.

A few patients expressed anxiety about the future; the lack of a cure was mentioned, as were worries about other conditions getting worse because of the treatment, for example renal problems. Facing an uncertain future, not knowing how long they would live and not being able to maintain expected lifestyle, often caused worry and low mood. Many patients openly questioned how much longer they had left:

“I just feel, you know, next week I might not be here...that’s my initial sort of fear, you know, oh my God how much longer have I got.” (pt 24).

One patient, summing up her quality of life as poor, expressed anger at her consultant. She had been told that she was not yet ill enough to have a transplant but said that she would like to take the risk of dying rather than continue with the quality of life that she had:

“I’m 53 and this is it, what you see, you know... she [transplant surgeon] was quite happy with the way I was, .. and so is [Dr] down at the [name of hospital]...he doesn’t have to live my life!” (pt 16).

For some it was having to rely on others that caused the greatest distress:

“...Sometimes you get very, very, low. I just sit back and watch the old girl do it. That hits me here thinking, I should be doing that, I know up here that I can’t and you get very depressed. If I were on me own I wouldn’t say I’d go suicidal but I’d be a lot worse off than I am now, if I were on me own I’d be in trouble” (pt 25).

Men seemed to talk more about depression whereas women more frequently mentioned fear and anxiety.

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Some patients had come through their depression and anxiety and adjusted to the life they had and its restrictions. In those cases, patients often attributed this to mediating factors, such as a supportive family or having sufficient material resources.

On interview some initially denied their feelings but, when the spouse was not present, admitted to being depressed. In one case the spouse contradicted her husband and revealed that he had been talking about suicide only a few weeks previously. Some patients were taking medication for the depression; others were receiving counselling or regularly seeing a Community Psychiatric Nurse.

### 6) Carer issues

Many carers reported that their lives had completely changed since their spouse or partner had developed heart failure.

Acute episodes were particularly stressful:

“...I rung him [the doctor] again I said ‘ his condition is worsening he’s really poor’. I can’t remember what he told me, ... yes he told me give him the heart spray, which I did, and then he start getting sick and then about .....I think it were about 4 o’clock in the morning, I rung the doctor again and said: ‘listen I don’t want this responsibility, I just can’t take it, cos the man is blue’” (cr 1).

Some carers were close to complete physical exhaustion through having to provide physical care, deal with medications, monitor symptoms and cope with lack of sleep:

“I have to do everything. If he’s in pain and calls out I go running, rub his chest and when his ankles ache I massage them. He’s in a lot of pain at night. Every fifteen minutes to half an hour he gets up. When he lies down he becomes breathless and it’s as though there isn’t enough oxygen. He gets all flustered and wakes up and I wake up with him. I rub his chest and help him to stand. It’s terrible at night. I wake up and sit there. When he manages to drop off then I lie down” (cr 33).

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A few carers reported having to give up work or other activities, which often led to them becoming isolated and lonely with little time for themselves. Some carers felt unable to leave the patient at all because they were not safe on their own, and some would have liked some time off, additional support from family members or access to respite care.

Particular difficulties arose where financial difficulties were experienced. All 5 Asian patients and carers mentioned this in relation to issues such as expenses incurred travelling to and from hospital appointments, lack of money because of unemployment or the cost of day to day living with a chronic and debilitating illness:

“It’s three years since he was ill. I bathe him, change and wash his clothes. I hold onto him as he walks. There are these bowls for urine... I keep them here for the night. I keep it all clean. Our bills can be three to four hundred pounds, gas, electricity, telephone. If only I could be helped a little. I find it impossible to wash clothes” (cr 35).

Carers often felt they had responsibility for the management of the patient and took over the drug treatments and controlled the patient’s activity level. Some appeared to have become overprotective, significantly reducing the patients autonomy and activity levels.

### 7) Asian patients

There were noticeable cultural differences in the way the five Asian patients and carers discussed heart failure, particularly when they talked about the meaning of their condition and beliefs about the effects of treatment.

Some had consulted a traditional healer, all mentioned a belief in Allah and had a more philosophical attitude toward their future and derived great comfort from their spiritual and religious beliefs, especially when thinking about death.

Some patients mentioned that the power of prayer, both their own and others’, was a major factor in their health. One patient attributed relief from severe symptoms to a combination of prayer and medication. The discipline and practice of Islam was mentioned in relation to knowledge and understanding about diet, exercise and

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general health. Included in this were comments about the importance of cleanliness, an inability to conduct ritual ablutions before daily prayers proved to be distressing for some patients. Difficulties carrying out prayer rituals were a serious concern:

“Yes. I am unable to do my namaz [obligatory prayers five times a day that require prostration]. Because you have seen how incredibly swollen my legs are.... I cannot prostrate. I have to offer my prayers sitting on a chair” (pt 33).

Other issues that were raised concerned lack of social contact and language difficulties. The availability of an interpreter was essential for all the Asian patients in order to understand heart failure and its treatment. Language difficulties restrict opportunities for support delivered by telephone. Although some patients could use family members to call for emergency help, others without English speaking family members reported waiting till morning when they could get a GP who spoke their language to get help with worsening symptoms.

**4.3.3** The impact of the specialist nurse service: six themes. There were 5 main themes concerning the impact of the service on patients and carers, and one specific to non-English speaking patients:

- 1) Knowledge & understanding, self-management skills
- 2) Communication with the nurse
- 3) Relationship with heart failure nurse
- 4) Ease of access to what you need
- 5) Recommendations for the service
- 6) Language difficulties

### **1) Knowledge & understanding, self-management skills**

Most of the patients said that the specialist nurse had improved their understanding and were able to describe the symptoms and the reasons for them, the medications they were taking and the need to make lifestyle changes.

A few patients appeared confused, especially about issues related to lifestyle and the causes of heart failure and some still had unhelpful misconceptions, a few putting their symptoms down to overwork or a natural effect of ageing. A number of patients

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could not remember exactly what they had been told, either by the doctor or the specialist nurse and some did not think that the information they got was relevant.

Most patients welcomed written information but a few found it unhelpful, stating it was either too much, the timing was inappropriate, or in the case of some elderly and all of the Asian patients, couldn't read it:

“I was a little bit worried the first time she came because I felt she overloaded me rather with information and by the time she went I was beginning to feel a little bit worried and a little bit despondent in a way... it was just that probably I didn't expect, you know, quite so much information probably.” (pt 28).

Younger men were more likely to talk explicitly about the reasons for heart failure and it's management and had often searched widely to supplement the information they had been given by the nurse. Women appeared to be more vague in their understanding of heart failure and relied on information they had been given by doctors or the specialist nurse:

“It's coming from the heart it's a build up of fluid because my heart...is not pumping the fluid out it's coming in at a certain rate but it's not going out fast enough so there is a build up so the liver swells up which is quite dangerous I have to weigh myself every morning and, er, just watch the weight” (pt 16).

As with younger men, younger women felt more able to ask for specific information; for example, about sex, particularly if they felt comfortable with the nurse.

Most patients felt they were better able to manage their condition after contact with the nurse. In part this was due to advice on salt and fluid intake and monitoring their weight. Not only were some patients able to recognise the increasing symptoms associated with fluid overload but a few had the confidence to regulate their medication themselves. This gave both them and their carers, a feeling of increased control and confidence:

Cr:“One of the best things she suggested was that [name of patient] weigh himself every day. No body suggested that before at all. So he does it every

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day, writes it down, he knows if it goes up a couple of kilograms you're getting fluid retention...but no body...I mean we never thought of it really, but it did, over the months, it used to build up and build up and he ended up back in hospital but now...he knows, you know, right away and then we phone [Nurse] and she alters...tells him the drugs to take, the diuretics. It is good because it stops him ending back up in hospital.

Pt: Well that gives you the confidence to be able to deal yourself with the illness really" (cr & pt 3).

It usually required several nurse contacts to educate and motivate the patients and carers to practice better self-care and it seemed particularly difficult for elderly patients, those with unstable heart failure and those who lived alone to learn self-management skills.

Many patients reported that they had not received useful advice on physical activity. Others had been given advice that was too vague, or ambiguous. Although many said they were sure they had been given information, when asked to repeat it they either couldn't or were hesitant and lacked confidence.

"Um, well he said mild exercise, you know, just do what you feel you can do without over-exerting myself...nothing specific and you know eat healthy and, which I do anyway" (pt 23).

Some were clearly trapped in a cycle of doing too much, followed by excessive rest to recover.

### 2) **Communication skills**

Communication was a very important issue for patients and carers and overall they were very positive about the nurses style. They perceived it as different to that of doctors, many were overtly critical of their doctors' abilities to communicate, saying that they felt they had not really understood their condition until they had seen the specialist nurse. This was either because they couldn't comprehend the terminology used by the doctor, or that the doctor talked over them, or the doctor simply didn't bother to explain. Some felt that the specialist nurses were more knowledgeable about

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living with heart failure and were able to interpret their symptoms in a more meaningful and relevant way than the GP:

“I don’t think they do it on purpose, but they just don’t realise that we don’t know what on earth they’re [doctors] on about. The next time she said, well it’s not failure it’s more of a decompensation or something...may as well have been in Russian” (cr 3).

“Well you go and see your local GP and say I’ve got a headache and he says... opens your papers and looks at what you’ve had in the past “how long have you had it?” “oh half a day” “I’ll give you some tablets, you’ll be alright”. That’s it. If I’d have said the same thing to [Nurse] he’d have said, “well what have you been doing differently just lately” this is how he would have attacked it. “How do you feel when you stand up? is it worse?” this sort of thing; and he asks questions; he’s very good...” (pt 27).

Some patients, felt that the nurse had not given them realistic expectations concerning their potential for progress or about the side effects of drugs like beta-blockers. Others felt that the nurse was not always happy to talk about their prognosis and were clear that they did not want to answer ‘how long have I got?’ types of questions.

Carers particularly appreciated the honesty of the specialist nurse about heart failure and its seriousness.

### 3) Relationship with the heart failure nurse

What many patients and carers seemed to value most was the quality of the relationship they had with the nurse. The most common words used to express how this affected them were, building up confidence, reassurance, being respected and being cared for. Nearly all patients and carers welcomed the opportunity to develop a type of relationship they had not previously experienced with health professionals.

The nurses were often seen as a valuable source of advice beyond heart failure issues and as someone who ‘is there for you’:

“...she’s been a strength really” (pt 10).

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“Well, it’s like a lifeline I’ve got now” (pt 11).

“I’m that so full of confidence with him [Nurse] I resigned from BUPA on the strength of him...you see that’s the other thing I mean, the attention I’m getting now terrific..... he’s got time to talk to me. He’s medicine himself.” (pt 27).

Many patients also praised their GPs and consultants, this varied according to centre. In one centre patients still wanted to see their GP as much as the specialist nurse, in another centre they would refer problems to the nurse in the first instance and some valued the opinion of the nurses above that of the doctor:

“Yes but the nurses probably have got more knowledge of the heart and treating the heart than the average GP...I do feel more confident with what they are saying, I really do” (pt 1 ).

#### **4) Ease of access to what you need**

The ease of access, the regular monitoring and the continuity of care were highly valued aspects of the specialist nurse service. The fact that they could count on seeing the same nurse who knew their “case” and had time for them was greatly appreciated.

“The reassurance that there is someone you can speak to that there is someone there at the end of a phone, not necessarily to get him out, but someone at the end of the phone saying I’ve got these symptoms what do you think” (pt 25).

Many patients, particularly the elderly and infirm and those without transport, appreciated not having to go to the GP or hospital for blood tests and routine check ups. Some patients said that the nurse’s ability to alter medications without the need for an appointment with the GP was a real bonus and saved them a lot of time. The regular monitoring of blood pressure, ankle swelling and lung sounds by the specialist nurse was reassuring and increased their belief that they were ‘doing okay’.

Specialist nurses often acted as an interface with the other health, social care and local authority professionals and referred patients for rehabilitation, physiotherapy, chiropody, counselling and palliative care.

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“.....she’s our sort of link between the doctor, well both the GP and the specialist and us, and she’ll do the leg work and telephone around because she knows who people are and she’ll get things done” (pt 7).

Some patients reported being in regular contact with the nurse through home visits and telephone calls. Others had ‘moved on’ to telephone contact only: this was acceptable to them as they knew that the nurse would resume home visits should they need it.

“I’m happy with the Heart Service, I am yes. And they haven’t forgot about me as I say [Nurse] calls regular do I need anything, do I want to come are you all right or all wrong so it’s not as if they’ve forgot about me” (pt 18).

Carers expressed great relief at not being entirely responsible for the patient and appreciated being able to check things with the nurse. As with patients they felt increased confidence in the management of heart failure and were reassured by the availability of the specialist nurse. One carer said:

“Without a specialist nurse who do you phone when you’re worried? You can’t phone consultant and say, “do you remember my dad?”. But you can phone [Nurse], she came here and sorted it all out...I would feel very lonely without [Nurse], I feel like she’s a friend. She tells me things that she maybe wouldn’t be able to tell them [indicates parents]. She’s very honest, not brutal, she just tells you the truth. ...I wanted to know, well, what is going to come like? And what we should and shouldn’t do, and she just tells us” (cr 13).

### 5) Recommendations for the service

Almost all the patients and carers reported being very happy with the heart failure nurse service. Very few could think of recommendations for change and were very pleased with the care they had received. One patient summed this up:

“I’m bursting to tell someone about how good the service is, what a difference it has made and I can’t think of an improvement” (pt 25).

He then went on to show comments that his specialist nurse had made in his patient booklet. These said how well the patient was doing, how motivated he was and

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concluded with “I salute him and his wife, they make a superb heart failure team”. The patient finished the interview by saying how good this made him feel and added: “...makes me feel a part of it, great isn’t it?” (pt 25)

Some patients wanted better and more specific advice on lifestyle issues, particularly diet and exercise, and others requested further information about benefits or home care.

One lady had not had regular visits from the specialist nurse and whilst she was not too concerned about this as she was managing well, she did feel strongly that there should be “system” for keeping patients informed if the nurse was unable to visit. One patient mentioned the lack of cover “out of hours” but added that he understood that this was not practical within the current service provision.

Only a couple of carers explicitly mentioned respite care as something they would have liked to be added to the service, but it could be inferred, from the distress and desperation that was often revealed by the interviews, that there was a huge need for carer support in the form of respite care.

A major concern for several patients and carers was that the service might become a victim of it’s own success. They felt that the nurses may spread themselves too thinly, possibly resulting in a failure to continue providing the present high standard of care.

### **6) Language difficulties for Asian patients**

Only a few features differentiated the views and needs of Asian patients. Two patients mentioned the specialist nurse explicitly and were very happy with the care they had received. One stated that since she had been seeing the heart failure nurse she had not had to be admitted to hospital at all, previously she had been going into hospital every few weeks. Six months later this patient’s condition had improved to the point where she was able to visit friends, go to the Mosque and even join a night class.

It was clear that for many the effectiveness of the service was highly dependent on access to interpreters. Some patients in Bradford had developed an excellent

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relationship with a regular interpreter who accompanied the specialist nurse and appeared to treat him as another specialist nurse or doctor. The interpreter made the appointments by phone and patients could phone him directly if they need to. He has taken part in some training about heart failure and also advised patients on claiming benefits.

### **4.4 Findings from second interviews**

All patients and carers previously interviewed were contacted by telephone and their views discussed briefly. A few patients either declined further interviews or were too ill to participate. We went on to interview those patients and carers who had either seen the specialist heart failure nurse since their last interview, had experienced a major change in their condition or who said they wanted to make additional comments. Thus, second interviews were conducted with sixteen patients and 6 carers about five months after the first. The focus of the second interviews differed in that we were keen to discuss any changes since the previous interview. The main themes arising from these interviews were:

1. Relationship with heart failure nurse
2. Changes in health and quality of life
3. Continuity of contact with heart failure nurse

#### **1) Relationship with heart failure nurse**

Most patients and carers continued to feel extremely positive about their relationship with the nurse and felt supported and reassured by the sustained contact. It was clear that the sense of comfort, partnership and trust had continued to develop.

Many had come to rely heavily on the nurse, both as a source of information and, as one patient said, a friend:

“I change the medication, well it’s a security blanket in a way, she’s there when you need her you know, not just for management of my health but for other things as well. She’ll find out things for you from the health authority, [Doctor] or whatever and get back to you, er sometimes she’ll just email with a message or whatever...she does things like that not directly linked with the condition - it’s all to do with every day living” (pt 3).

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Most patients appeared to recognise the specialist function of the nurse and had realistic expectations of what the service could provide in relation to the management of their heart failure. A patient who initially had felt that the nurse had been uncomfortable listening to him talk about emotional issues, later acknowledged and appreciated that this was one of the limitations of her role and appreciated her clarity in maintaining appropriate boundaries:

“... I don't think it's fair on her to expect her to be a social worker, or a psychologist. I've got access to psychologists if I want one. That's true professionalism, that's what professionals do. You know where the boundaries of your own skill are and you stick behind them” (pt 6).

One patient had been unhappy with the service at first interview asserting that the heart failure nurse was a waste of time. Not only had she left without telling him but also he felt that she had been evasive and unhelpful. However, he reported a dramatic improvement since seeing a different nurse:

“Can't praise [Nurse] highly enough, she really is an angel. When she came to see me and checked my ankles she even put my socks on...you couldn't have a better advert for the service than [Nurse]!” (pt 11).

A notable exception was an area where the hospital-based nurse had no community-based counterpart and had no time to visit patients in their homes. In most cases patient and nurse had not formed a relationship. In one case the patient had not seen or heard from the nurse in the months following discharge and when readmitted with worsening heart failure had not been contacted.

### 2) **Changes in health and quality of life**

Several patients reported a marked improvement in their heart related health since seeing the heart failure nurse, especially in relation to medication use and staying out of hospital. Much of this appeared to be the result of better knowledge and an increased confidence in managing symptoms and daily activities. Many felt that the regular contact had improved their ability to manage their heart failure. A patient, who, at first interview, had been physically very incapacitated, frequently admitted to hospital and extremely worried about her deteriorating health, had progressed to the

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point where she was able to walk to the shops, and felt so motivated and confident that she had also joined a night class:

“I never used to [cook], I was feeling dizzy and before I couldn’t cook for anyone now I can cook for 15 people...” (pt 26).

Another patient who required almost continuous oxygen and was more or less housebound, expressed her delight at how the specialist nurse had organised a wheelchair. She could now go out with her grandson and felt much better mentally:

“...for being out just meeting people and seeing what’s going on” (pt 29).

This patient also benefited from weekly visits to a local Hospice a facility that the specialist nurses had organised for heart failure patients. This meant that she was able to talk to others who were seriously ill with heart failure, enjoy relaxation classes and have an assisted bath, something she had not been able to do for months.

Some patients continued to have a poor or worsening quality of life. Some of this was due to their co-morbidities which in many cases caused great pain. Several patients felt they were constantly having to battle with the side effects of the drugs they had to take. Despite all this, they still appreciated the care of the nurses.

### 3) **Continuity of contact**

For some patients contact was still very regular and involved frequent home visits, for others regular telephone calls at six-weekly intervals seemed to be the norm and for a few contact appeared to be gradually tailing off. There appeared to be a group who would initiate contact with the specialist nurse and another that relied on the nurse ringing them. Most patients appeared to be satisfied whatever arrangements had been made.

“She’s coming back 4 times within the next year, that will be every 3 months. I generally have my blood pressure taken every 3 months. I did not have to worry like, she takes that as well, and she says after that everything being ok it’ll be a yearly... and then it’ll tail off eventually go back to your GP unless anything untoward happens.” (pt 2).

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The majority of patients felt that they knew when to ask for help and that they were confident enough to contact the specialist nurse if they were worried. Most said that if they had problems with their heart they would contact the nurse, but if it was anything else they would contact their GP. Even if they didn't see the nurse face to face being able to talk on the telephone helped a lot. Having an arrangement where nurses covered for their colleagues who were absent was also mentioned as being helpful.

A few patients did not seem to be aware that they could contact the nurse directly and still used their GP as the first point of contact. Others said that they either hadn't thought about contacting the nurse over problems or felt they were taking up too much of the nurse's time.

“I should phone her more often shouldn't I? But I don't, you know, it's like this - I could phone her up every time I felt down in dumps, can I?... 'cos I think she's got a lot of people to look at in the hospital hasn't she?” (pt 8).

### 4.5 Findings on medications, readmissions and deaths

The percentage of patients taking an ACE inhibitor at first visit ranged from 77–92%, with a range of 26-70% of patients on the minimum dose of beta blockers. No data was obtained on the proportion of patients who achieved evidence based doses, but nurses reported in general that most patients were stabilised on an optimal dose for the individual through negotiation and recognition of the need to balance unwanted side effects with recommended doses. This was particularly an issue with older persons who have a lower tolerance of beta-blockers.

The all cause readmission rate for the total number of patients seen over the year was 35%. This rate varied across centres from 14–57% with some patients having been followed up for one year and all a minimum of 3 months. Centres with more elderly patients with complex, unstable heart failure and comorbidity had higher rates.

Deaths rates (all cause) varied from 5% to 17%, with an overall rate of 13%. In general it would appear that patients managed by the heart failure specialist nurses have lower unplanned readmission and mortality rates than the national average for patients with heart failure.

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Summaries for each centre are in Appendix 3.

# THE PROCESS EVALUATION

## NURSES AT THE START OF THE PROJECT:

“Being out there, taken from my comfort zone, I felt sometimes on an island, no-one else around, gone were those four walls.” (nurse 11)

“As your knowledge base improves you realise how little you know. What is difficult to achieve is supervised clinical exposure to almost fast-track your experience before you see patients by yourself. Especially when your role involves unsupervised home visits – it takes you so long and repeated visiting to make the smallest decision.” (nurse 13)

## NURSES 18 MONTHS INTO THE PROJECT:

"I think it's probably the most worthwhile job I've ever done, but it's also been the hardest. Learning how to do this job has been a real eye opener - a steep learning curve. But it is so rewarding, the patients are so appreciative when you can keep them out of hospital." (nurse 5)

"I'm gaining more knowledge and experience as time goes on. Job satisfaction is the biggest thing - I've never had such a great job. More or less every home visit you're thanked and praised for the service, for what they're getting." (nurse 8)

"There are patients that went in [to hospital] last year that won't have gone in this year because I'm more confident, and the GPs are more confident about ringing me." (nurse 1)

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## 5. The process evaluation

### 5.1 Methods

**5.1.1** Pilot site characteristics. Information was gathered on various aspects of service provision. This included: service configurations (hospital or community based clinics, home visits, telephone support), referral mechanisms, patient care pathways, medical therapy guidelines, and key components of the educational intervention. Dates nurses came into post and started to see patients were collected. It was also important to assess what skills and training are needed to make an effective specialist nurse, where they should be placed, and what nurse support arrangements appear to be best. Therefore the qualifications and previous professional experience of nurses were also gathered. The information is summarised below and appropriate parts of the raw data are presented in the appendices.

**5.1.2** Nurse field notes. Nurses kept a series of monthly reflective diaries recording any thoughts, feelings or observations that they may have in relation to their role that might be pertinent to a fuller understanding of the issues that they face in practice.<sup>14</sup>

The field notes had four main categories to act as prompts for the nurses:

- Record barriers or facilitators to effective working at organisational and individual staff and patient levels;
- Record main issues reported by patients and carers, or observed by nurse;
- Reflect on whether nurse feels adequately equipped to deal with patients (and carers) at all stages of their condition, and record any resultant training needs;
- Reflect on contacts with patients and other multi-disciplinary team members, their performance, the way the job is developing and any other issues.

The researcher inductively developed themes and coded the notes as they arrived monthly. At the end of the study a thematic analysis took place with two researchers agreeing coding and refining themes.

**5.1.3** Exit interviews. The themes from the nurse field notes were used to inform exit interviews with the post holders.<sup>15</sup> Exit interviews took place with all nurses after they had been in post about 18 months. Interviews were recorded and transcribed

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verbatim. Transcripts were coded line by line, a coding schema was developed and refined and data analysed using cross case theme analysis.

## 5.2 Findings

### 5.2.1 Pilot site characteristics

#### Service Format

There was considerable variation between sites. In both rural sites nurses had a slower start in patient referrals. They had smaller caseloads; relatively stable patients; and referrals from cardiologists only. They saw the patients on the wards and then at home and up-titrated the drugs in hospital based heart failure clinics. In one centre the two nurses did not see patients for the first 4 months and spent that time promoting the service and getting to know key community staff. In the other, the two nurses started to see patients in hospital clinics after a few weeks, and did not start home visits for 2 months. Both these sites reported excellent clinical support and some clerical support. In one the nurses were based in primary care but their office was very close to the hospital and the other was hospital based. Protocols and medical therapy guidelines were developed early. Large geographical distances were covered by the nurses in these areas.

In one city, three new nurses were appointed and a fourth nurse 'adopted'. Two of the nurses were placed in different hospitals and worked mainly in heart failure clinics from day 1, with some ward visits to see patients pre-discharge. These nurses felt that they were being used as additional general cardiac nurses, primarily in an educational role and not as heart failure specialist nurses. Two more specialist nurses were recruited, the intention being that they would have a community role. One left the post after a few months, the other went on sick leave followed by maternity leave. Neither were replaced during the study period. This put huge pressures on the remaining nurses who saw large numbers of patients in clinics but had little time for home visits. They had no clerical support and, for many months the consultants they worked with could not agree on protocols or medical therapy guidelines, further restricting the nurses' role.

In another urban area with no tertiary centre, areas of high deprivation and minority ethnic groups, the three nurses were PCT based. Patients from this centre were older,

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many had unstable heart failure needing complex management. They did not start to see patients until they had been in post for 5 months. They encountered some initial difficulties obtaining referrals from hospital wards. They had supportive steering groups and local PCTs with a history of multi-disciplinary collaborative working. The nurses had quite a large geographical urban area to cover and soon found visiting the hospital to promote the service and pick up referrals too time consuming. One nurse had a high number of patients requiring interpreting services and visits to these patients usually took about two hours.

The other centre covered inner city, suburban, and rural PCTs. The three nurses here were based in 3 different PCTs and often had difficulties accessing medical staff and regular clinical support. Referrals were from cardiologists, physicians, wards and in one PCT, GPs. There was no clerical support available. Nurses saw patients in hospital wards and outpatient clinics and aimed to provide home visits within 48 hours of discharge. They had to obtain permission to change drugs doses and trying to contact GPs for permission was very time consuming. The three nurses had very different sized caseloads within a few months, with the nurse in the inner city area becoming almost overwhelmed, while another nurse received few referrals but had a large rural area to cover.

All of the centres had different protocols for: the number of home visits; whether patients gradually had fewer home visits and the balance between home visits, clinic visits and telephone follow up.

### **Content of interventions**

All centres reported that they provided a comprehensive care package involving individually tailored education, monitoring of symptoms and blood biochemistry. Written information was given to all patients and during the study period three centres developed patient held record cards.

### **Nurse qualifications and experience**

The nurses had varying qualifications ranging from RN, a Degree in Nursing, various diplomas to an MSc in Advanced Nursing. All had worked on cardiology wards, three had worked in cardiac rehabilitation and one had been a cardiovascular nurse in

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primary care. Two of the nurses had previous experience of working in the community.

**5.2.2** Nurse field notes. In general nurses reported that they were learning every day and finding the job both challenging and rewarding. Three broad themes emerged from nurse field notes:

1. Organisational issues
2. Training/induction
3. Patient issues.

### 1) **Organisational issues**

Initially the nurses reported difficulties of having no one to 'pave the way' for their arrival. This meant they often had nowhere to work, no phone, no administrative support, no computer access and no patient database.

Many nurses reported that initially the liaison with Primary Care staff was difficult. Some felt that GPs were hostile, dismissive or sceptical about the service and the benefit of non-pharmacological management, others seemed wary about the nurses potential effect on prescribing budgets. Nurses had to clearly define their role or would be used as a dyspnoea or general cardiology nurse. Difficulties were also encountered with getting to know hospital staff and getting them to refer patients to the service, and having an honorary contract with secondary care was said to improve access.

### **Management issues**

Several nurses reported feeling that they were being 'pulled from all directions' - trying to satisfy the demands of acute and primary care trusts, community staff and the BHF.

A clear management structure, clinical and secretarial support, good IT, a local steering group or a managed clinical network were all regarded as essential. The importance of access to 'a multi-disciplinary team' was frequently emphasised, as was

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support from the other heart failure nurses, district nurses and the clinical lead. Some nurses had regular meetings with clinical psychologists and palliative care teams.

Even though, by the end of the study period, most areas had arrived at locally agreed referral systems and medical therapy protocols, the reality was that these were not always complied with or accepted by some GPs or secondary care staff.

### **Roles and workload**

There was a wide variation in the roles, responsibilities and workload of individual nurses. Some were prescribing and taking clinical decisions whilst others offered advice to GPs or consultants of the need to change medications. These nurses often had to wait in the patients' homes until the doctor phoned back to authorize the change. This led to frustration and a feeling that their time was being wasted. Similarly, in some areas, large distances were being traveled simply to take bloods and then deliver them to the lab. In some areas solutions had been found, for example, liaising with the district nurse to carry out this service.

The speed with which nurses were expected to take on their new role varied widely as did the number of new patients they were expected to take on each week.

The BHF provided an educational programme, through Caledonian University, for all of the nurses and this was highly appreciated but it did not cover all of the aspects that were new to individual nurses, most of whom were taking on a very different way of working.

### **Time pressure**

As nurses began to see more patients and undertake more home visits, as well as dealing with their academic course assessments, many felt that they did not have enough time for both and were concerned that, due to time pressures, they might not be able to care for patients adequately. Nurses reported taking clerical tasks, such as letter writing, home in the evenings. They frequently used phrases such as 'overwhelmed' and 'burned out'.

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Time pressures were compounded by problems with communication. For example, there was no written information on heart failure in South Asian languages. The nurse had to give all information verbally with much repetition to check understanding at each visit. Management of medication was particularly difficult when frequent changes were needed as many patients could not read instructions on labels. There were other often unexpected cultural issues, for example, many patients of South Asian origin did not wish to be visited before 10.00 in the morning, as they got up early to pray and then went back to bed.

### **2) Training/induction**

Some nurses reported finding the move from acute services to working in the community visiting patients in their home very challenging. A need for training in clinical assessment was raised by some nurses. As one nurse said:

“As your knowledge base improves you realise how little you know. What is difficult to achieve is supervised clinical exposure to almost fast-track your experience before you see patients by yourself. Especially when your role involves unsupervised home visits – it takes you so long and repeated visiting to make the smallest decision.” (nurse 13).

It was suggested by some nurses that the academic course and training in assessment should have been completed before the nurses started to see patients rather than simultaneously.

Nearly all of the nurses expressed a need for more training in palliative care. Some also expressed a need to know more about psycho-geriatric problems, rehabilitation techniques and other therapies that would help.

### **3) Patient issues**

Many of the nurses reported being surprised at how ill and unstable some patients were. Most patients were very worried about acute flare-up and the nurses felt disappointed if a patient had to be readmitted to hospital. Sometimes GPs would arrange admission without consulting with the nurse. Often the nurse felt that this had been unnecessary and traumatic for the patient, who could have been managed with home visits and changes to their medication. Similarly, nurses sometimes returned

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from leave to find that a patient had been readmitted because there was no other nurse in the community able to help them and therefore the family or the GP had simply phoned for an ambulance. A couple of patients did not contact the nurse when they felt worse, which was frustrating for the nurses who felt the subsequent readmission could have been avoided.

Nurses reported a number of issues for patients around medications. Poly-pharmacy was a common problem, others were the patients being reluctant to change doses of drugs when they were already feeling well, or finding the constant changes confusing. Up-titrating drugs to guideline levels was often difficult because of the effect on co-morbidities. As nurses became more confident and experienced, they often acted as an advocate for patients, negotiating a lower dose with the doctor.

One of the most frustrating situations was when a referral was not made whilst the patient was in hospital and the consultant then referred the patient after an outpatient clinic visit that might be weeks or months after discharge. This made it impossible to work according to European Task Force Report Guidelines, which state that the first visit should be within 10 days of discharge.

**5.2.3** Exit interviews with nurses. Much of the information arising from the exit interviews with the nurses echoed the themes already reported from the field notes and these are only repeated here where there was evidence of a change of view or a new way of working.

With the benefit of greater experience many had developed clear views about how a service should be organised.

In general the nurses had gained much confidence and had enjoyed the challenges of growing into the post. Those based in secondary care running ‘one stop diagnostic clinics’ were less satisfied with their role and one reported being ‘just a ‘handmaiden to the consultant’.

The themes arising from the interviews were:

1. Personal and professional development.

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2. Effective working, facilitators and barriers
3. Patients and carers

### 1) Personal and professional development

The first 18 months were a very challenging time for the nurses. Having to carry out clinical assessments on their own in a patient's home was outside of their comfort zone, and many found it a frightening experience:

“Being out there, taken from my comfort zone, I felt sometimes on an island, no-one else around, gone were those four walls.” (nurse 11).

The training in Glasgow had provided the necessary theory, some nurses felt that time learning how to apply it to real cases would have been useful, i.e. more interactive case studies and shadowing established heart failure nurses. There were suggestions that some of the training would have been more useful after they had seen a few patients, as they could have brought problems for discussion. Nurses reported needing more guidance on:

- clinical assessment skills
- history taking and summarising it
- problem solving skills –weighing up cost-benefits for each patient individually.

Some nurses felt this would be best acquired by: doing ward rounds with doctors; supervised clinical examinations; using the HARVEY simulated patient to hear a variety of heart sounds; a structured clinical assessment course; a video showing these skills; training on interpreting tests and having regular clinical supervision meetings.

Several reported that shadowing the district nurses had been the most useful part of their induction as it taught them how to liaise with GPs, social services and voluntary agencies. Many nurses said that ideally specialist nurses should have previous experience of working in the community.

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Most nurses felt the need for a career ladder. A few mentioned the potential for becoming elderly care nurse practitioners, nurse practitioners in chronic disease management, or cardiology nurse consultants.

The nurses differed in their attitude to the role, some knew they must set personal boundaries and find others to refer problems to, whereas others saw their role as being the key worker and always tried to sort a problem themselves; sometimes this led to them feeling overwhelmed.

As nurse 2 said:

“ I need to know, as a safe practitioner, when do I need to call someone in?”

### **2) Effective working**

Nurses felt that building a caseload slowly and using the early time in post to get to know the local resources in an area was important. Some felt that they should have been based with community nursing teams rather than at PCT headquarters. Even though theoretically the PCTs had line management and support systems for them, in reality nurses were often isolated and left to their own devices.

Many of the issues around responsibility were still evident. Nurses were aware that sometimes they were asking a GP to support a therapeutic decision which he or she did not have the knowledge, or confidence, to confirm. Some reported that doctors felt that up-titrating ACEs and Beta blockers would simply ‘prolong the misery’ for their sick elderly patient, leading to a worse quality of life due to hypotension and renal problems. Similarly, some GPs were reluctant to add a drug for depression to a patient’s already complicated medication, even though the nurse thought it necessary. The conflict between guidelines and ‘targets’ for different chronic illnesses could lead to ludicrous situations. For example; in one area a practice nurse doing ‘falls assessment’ as part of the NSF for Older People stopped a patient’s medication that had been ‘painstakingly up-titrated over 20 visits’.

All nurses stressed the importance of working as a team with the other heart failure nurses in the area. This provided professional and emotional support, cover for leave and opportunities to network and share ideas.

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All nurses commented on the importance of the first home visit, to see how the patient was coping and to assess the patient's opportunities for self-management. Several nurses had learned to limit the amount of information given at the first visit.

Most nurses felt that a maximum of 2 new patients a week ensured a manageable caseload, with no more than about 100 patients in a caseload at any one time. Frustration with the slowness of social services was frequently mentioned, with some patients dying before receiving a first assessment visit.

Many teams had developed local solutions and innovations to improve patient care and develop their capacity. Some examples included:

- establishing a weekly heart failure support group in a hospice providing day therapy, palliative care, education and support for patients and carers. This achievement has been acknowledged by the model being included in the NHS Modernisation agency's recommendations for collaboration
- liaising with rehabilitation teams to provide services including psychology and physiotherapy for patients and carers
- building capacity within Primary Care by training District, Practice and CHD lead nurses to manage uncomplicated patients
- providing star-coded medication dosette boxes for patients unable to read instructions
- establishing joint home visits with Diabetes or Palliative care nurses
- establishing ways of speeding social services assessment visits for the more urgent cases
- establishing systems of getting district nurses to take bloods for Us & Es which saves a special visit
- training ambulance teams, and district nurses on fast response teams, about the service and the resulting implications for information to take in to hospital if a patient needs to be admitted
- setting up a peer education project

### 3) Patients and carers

Nurses felt that they were valued by their patients who repeatedly thanked them and told them they had made a difference. All reported feeling they had achieved good rates of ACE and Beta-blocker usage and a marked reduction from the previous rate of readmission.

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Nurses reported that most patients fell into two distinct groups:

1. younger cardiomyopathy and post-MI patients who could be put on optimal treatment and educated to a good level of self-management. These patients need fewer home visits and could attend clinics.
2. the other group tend to be the elderly patients with co-morbidities, often living alone, sometimes in significant hardship, who found it difficult to understand and implement recommended changes, were often unable to perform self-management tasks, and who need more home visits to stabilise them and get them on optimal doses of evidence based medicines.

Carers greatly appreciated the advice and availability of the nurse, often ringing the nurse when the patient would not. Some carers relied on the psychological support of the nurse.

Nurses who had cared for patients through the end of life reported how grateful the families had been for the support and co-ordination of care they had provided.

One carer, not interviewed as her husband had died before the interview could take place, said of the nurse in a letter to the researcher:

“We started the journey together and ended it together”

Nurses often negotiated an increase in medication levels by explaining that this should result in less readmissions and longer survival, but as one nurse put it:

“ You purchase an extension of life, a theoretical improvement, by getting people onto target doses of evidence based medicine....at a cost of a frank deterioration in symptoms and in quality of life.” (nurse 13).

This can lead to a complicated power dynamic where the patients want to please the nurse by being compliant and feel it is their fault if they fail to improve, or feel worse. Good communication skills and reassurance are essential in these cases.

# Conclusions & Recommendations

# THE BHF HEART FAILURE SPECIALIST NURSE

## 6. Conclusions

- patients and carers greatly valued the heart failure specialist nurse service which provides them with many benefits
- patients were reassured by regular monitoring, having a key nurse with whom they could build a relationship, who provided continuity of care and who was easily accessible
- patients had high levels of anxiety and depression and very low levels of activity
- carers welcomed having the nurse with whom they could share responsibility for the patient
- in some centres a lack of preparation or local agreement about the role of the nurse caused difficulties in establishing an effective service
- after initially feeling challenged by the role, the nurses now feel that they have become assured practitioners, feeling respected by patients, GPs and consultants
- nurses are having an impact on patient health and well being by providing support and co-ordinating multi-disciplinary care
- the nursing role calls for considerable knowledge and a number of skills. The nurses valued the training they received and identified a number of additional needs
- nurses are improving local services for heart failure patients in general as well as at an individual level

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## Recommendations

Our recommendations fall into 3 main areas:

### *1. Organisational*

- there should be professional support; a managed clinical network or multi-disciplinary steering group; referral and treatment protocols and a set of roles and responsibilities for nurses agreed locally prior to the appointment of nurses
- there should be a structured induction period including an introduction to the local community systems and key stakeholders in primary and secondary care
- there should be a phased approach to building a caseload
- the service should span the primary/secondary care divide. This can be achieved by PCT based nurses spending some time in secondary care
- patients in general medical or care of the elderly wards are often missed and there is a need for a person based there to identify and refer relevant patients to the service
- the current ad hoc method for developing integrated assessment and clinical skills should be replaced with regular, structured occasions for learning with an experienced mentor
- there should be regular clinical supervision with a cardiologist, registrar or GP with special interest to discuss difficult cases. It is helpful if these doctors act as 'champions' for the specialist nurse service
- access to consultant advice via a mobile phone would be very helpful
- all nurses should have mentoring and support allowing the discussion of issues around concerns such as, feelings of failure if patient does not improve, the death of a patient, maintaining appropriate boundaries of care
- IT, clerical and administrative support should be available
- consideration should be given to developing a career pathway for heart failure specialist nurses.

### *2. Training*

Education and training needs reported by the nurses included:

- communication skills to enable discussion of prognosis & patient expectations
- more on palliative care and helping patients with 'end-of-life' issues
- the skills to identify and meet psychological and rehabilitative needs including physical activity

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- a video showing good clinical assessment and history taking skills would be a useful addition to their training
- training in simple cognitive-behavioural techniques, particularly to promote physical activity, problem solving and psychological self-help
- training in cultural awareness
- training to use assessment measures to determine the patient's needs and provide an audit of outcomes

### *3. Service delivery*

- the treatment components provided should be based on an assessment of each patient's individual needs and risk stratification to create a care plan discussed and agreed with the patient and carer. Whenever possible this should take place at the first visit
- services should be organised to optimise patient education and rehabilitation, enhancement of self-management skills, optimising medications, symptom control and maintaining close follow up
- nurses acting as 'case managers' could be expanded
- less information could be imparted in the first visit and education could be spread over several visits
- some patients and carers were unable to read and video or audio-taped information should be made available in appropriate languages
- patients revealed significant unmet psychological needs. Simple cognitive behavioural management provided by the nurses may be helpful. Otherwise patients should be referred on to psychology or psychiatry services
- resources and training should be made available to enable nurses to coordinate a multi-disciplinary team approach
- caseloads should reflect the case mix of mild and severe disease and travelling times
- a more flexible approach to when and where patients are seen using a mixture of home, clinic and telephone support according to the patients needs, might reduce time pressure on nurses

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## List of Appendices

Appendix 1 membership of Research Advisory Group

Appendix 2 study recruitment process

Appendix 3 performance data from centres

Appendix 4 patient treatment protocols

# THE BHF HEART FAILURE SPECIALIST NURSE

## Appendix 1

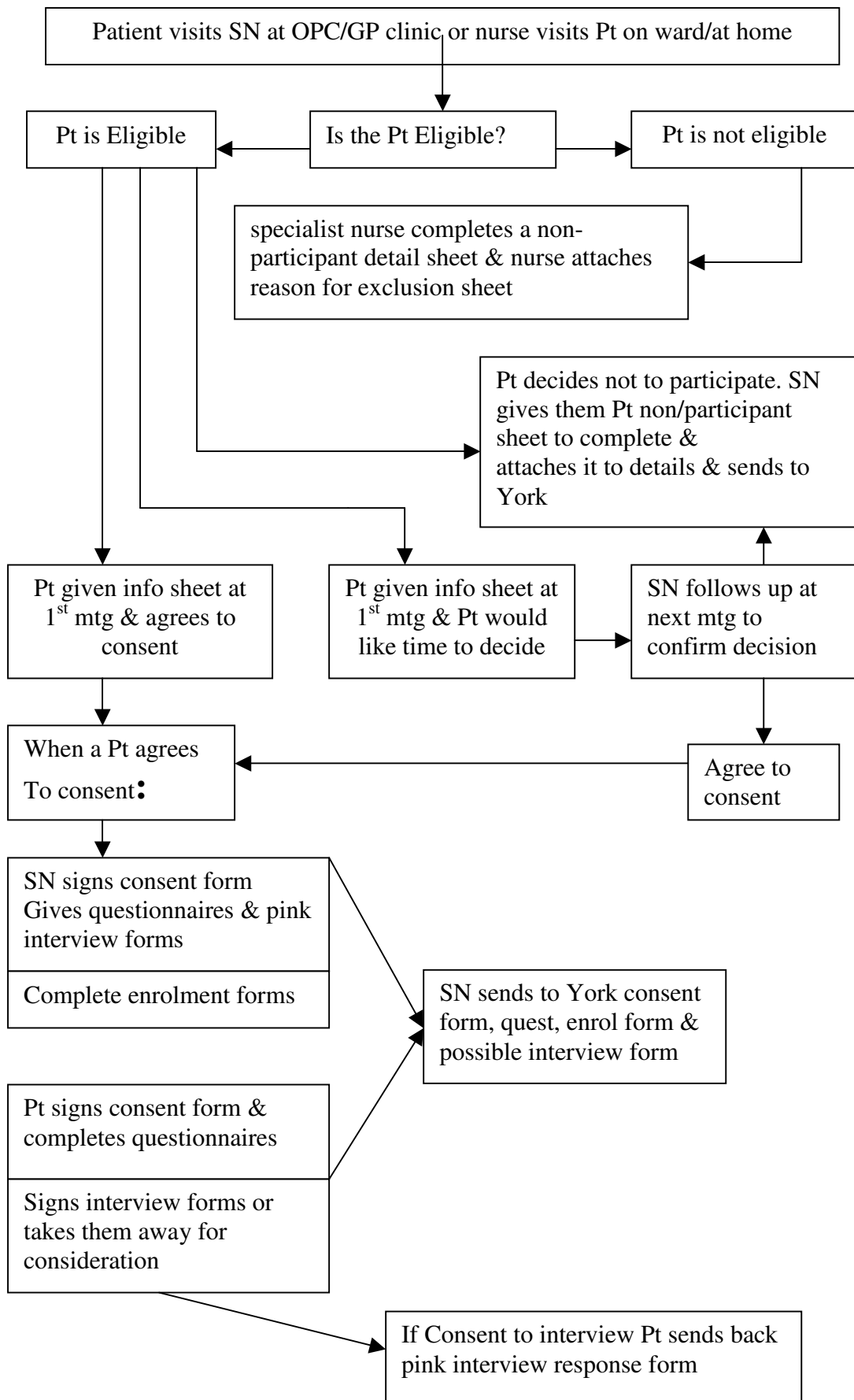
### Research Advisory Group

We wish to thank the Research Advisory Group for giving their time, expertise and advice which was invaluable in supporting the research. In particular, we wish to thank Mr and Mrs Hodgson for their help in understanding the patient & carer perspective.

Dr Karl Atkin	Associate Director, Centre for Research in Primary Care, Nuffield Institute for Health Advice on ethnic issues
Mr Peter Bailey	Representative from the New Opportunities Fund (Replaced Mr Steven Browning)
Ms Lynda Blue	BHF Heart Failure Advisor Advice on heart failure specialist nursing
Dr Mick Davies	Consultant Cardiologist, Chairman of the British Society of Heart Failure Medical advisor
Ms Shai Davies	Head of BHF Nursing Services
Mr Mick Hodgson	Patient Representative
Mrs Margaret Hodgson	Carer Representative
Prof Bob Lewin	Professor of Rehabilitation, University of York Director, BHF Care & Education Research Group
Dr Jeremy Miles	Dept. of Health Sciences, University of York Statistical analysis and advice
Dr Jane Noyes	Dept. of Health Sciences, University of York Advisor on qualitative research methods
Ms Jill Pattenden	Dept of Health Sciences, University of York Research Fellow, BHF Care & Education Research Group Principle Investigator
Ms Helen Roberts	Dept of Health Sciences, University of York Advisor on palliative care issues, some data collection and analysis

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## Appendix 2 Study Recruitment Process



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## Appendix 3 performance data from centres

### Bradford

#### Number of patients seen by nurse (in approximately 10-12 month)

Nurse	Enrolled	Not enrolled	Total	Mean No. Contacts (range)
1	14	60	74	6 (3-17)
2	18	33	51	6 (3-8)
3	22	38	60	7 (1-20)
<b>Total</b>	<b>54</b>	<b>131</b>	<b>185</b>	

#### Readmissions and deaths by nurse (all cause)

Nurse	Enrolled		Not enrolled	
	Readmissions No. (%)	Deaths No. (%)	Readmissions No. (%)	Deaths No. (%)
1	9 (64)	4 (24)	42 (70)	16 (28)
2	9 (50)	2 (11)	9 (27)	3 (9)
3	23 (100)	3 (14)	13 (34)	4 (11)
<b>Total</b>	<b>41 (76)</b>	<b>9 (17)</b>	<b>64 (49)</b>	<b>23 (18)</b>

Overall readmission rate 57%, overall death rate 17%

#### Heart Failure Classification of patients

NYHA	Enrolled	Not enrolled	Total	interviews
I	2	2	4	1
II	21	20	41	2
III	19	31	50	4
IV	4	17	21	2
Missing	8	61	69	

#### Socio-demographics of patients

	Study Participants	Non -Participants
Median Age (Range)	80 (27-95)	Not Known
Ethnicity	White 64% Asian 11% 25% unknown	White 83%, Asian 11%, Afro/Caribbean 6%
Alcohol abuse	current 2	current 4, former 9
Smoking	current 9, former 25	current 17, former 25
Overweight	3	26

#### Medications at first visit (enrolled patients only)

	ACE	Beta Blocker
Yes	85%	26%

Interviews were with 9 patients: 5 white, 4 Asian; 6 male, 3 female

# THE BHF HEART FAILURE SPECIALIST NURSE

## Birmingham

### Number of patients seen by nurse (in approximately 10-12 month)

Nurse	Enrolled	Not enrolled	Total	Mean No. Contacts (range)
1	18	171	189	6 (3-17)
2*	6	1	7	6 (3-8)
3	51	100	151	7 (1-20)
4**	8	7	15	
<b>Total</b>	<b>83</b>	<b>279</b>	<b>362</b>	

\*lengthy absence from work \*\*left after 6 months, 2 months after data collection started

### Readmissions and deaths by nurse (all cause)

Nurse	Enrolled		Not enrolled	
	Readmissions No. (%)	Deaths No. (%)	Readmissions No. (%)	Deaths No. (%)
1	4 (22)	1 (5.5)	55 (32)	20 (12)
3	11 (22)	5 (10)	45 (45)	18 (18)
4	Unable to obtain	2 (25)	Unable to obtain	0 (0)
<b>Total</b>	<b>15 (18)</b>	<b>8 (10)</b>	<b>100 (36)</b>	<b>38 (14)</b>

Overall readmission rate 32%, overall death rate 13%

### Heart Failure Classification of patients

NYHA	Enrolled	Not enrolled	Total	interviews
I	3	5	8	1
II	29	19	48	3
III	40	57	97	2
IV	9	50	59	2
missing	2	148	150	

### Socio-demographics of patients

	Enrolled	Not enrolled
Median Age (Range)	69 (25-83)	Not Known
Ethnicity	Information supplied for all patients together: White 77%, Asian 13%, Afro/Caribbean 10%	
Alcohol abuse	current 1, former 9	current 11, former 48
Smoking	current 9, former 26	current 22, former 72
Overweight	24	59

### Medications at first visit (enrolled patients only)

	ACE	Beta Blocker
Yes	92%	70%

Interviews were with 8 patients: 6 white, 2 Afro-Caribbean; 5 male, 3 female

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## Causeway

### Number of patients seen by nurse (in approximately 10-12 month)

Nurse	Enrolled	Not enrolled	Total	Mean No. Contacts (range)
1	14	9	23	6 (1-7)
2	24	6	30	5 (3-12)
3	1	11	12	5 (1-6)
<b>Total</b>	<b>39</b>	<b>26</b>	<b>65</b>	

### Readmissions and deaths by nurse (all cause)

Nurse	Enrolled		Not enrolled	
	Readmissions No. (%)	Deaths No. (%)	Readmissions No. (%)	Deaths No. (%)
1	5 (36)	0	0	1 (11)
2	12 (50)	4 (17)	2 (33)	0
3	0	0	4 (36)	0
<b>Total</b>	<b>17 (44)</b>	<b>4 (10)</b>	<b>6 (23)</b>	<b>1 (4)</b>

Overall readmission rate 35%, overall death rate 8%

### Heart Failure Classification of patients

NYHA	Enrolled	Not enrolled	Total	interviews
I	3	1	4	
II	24	16	40	3
III	11	9	20	4
IV	1	0	1	

### Socio-demographics of patients

	Study Participants	Non -Participants
Median Age (Range)	75 (51-85)	Not Known
Ethnicity	All white	All white
Alcohol abuse	current 3, former 2	current 0, former 4
Smoking	current 2, former 19	current 2, former 9
Overweight	14	9

### Medications at first visit (enrolled patients only)

	ACE	Beta Blocker
Yes	77%	49%

Interviews were with 7 patients: all white; 4 male, 3 female

# THE BHF HEART FAILURE SPECIALIST NURSE

## Dumfries

### Number of patients seen by nurse (in approximately 10-12 month)

Nurse	Enrolled	Not enrolled	Total	Mean No. Contacts (range)
1	41	10	51	6
2	30	18	48	n.s.
<b>Total</b>	<b>71</b>	<b>28</b>	<b>99</b>	

### Readmissions and deaths by nurse (all cause)

Nurse	Enrolled		Not enrolled	
	Readmissions No. (%)	Deaths No. (%)	Readmissions No. (%)	Deaths No. (%)
1	5 (12)	4 (10)	1 (10)	1 (10)
2	4 (13)	0	4 (22)	0
<b>Total</b>	<b>9 (13)</b>	<b>4 (6)</b>	<b>5 (18)</b>	<b>1 (4)</b>

Overall readmission rate 14%, overall death rate 5%

### Heart Failure Classification of patients

NYHA	Enrolled	Not enrolled	Total	interviews
I	9	5	14	
II	35	13	48	3
III	20	6	26	2
IV	4	3	7	2
Missing	3	1	4	

### Socio-demographics of patients

	Study Participants	Non -Participants
Median Age (Range)	70 (42-88)	74 (64-86)
Ethnicity	All white	All white
Alcohol abuse	current 6, former 3	former 1
Smoking	current 14, former 34	current 8, former 6
Overweight	27	11

### Medications at first visit (enrolled patients only)

	ACE	Beta Blocker
Yes	86%	37%

Interviews were with 7 patients: all white; 5 male, 2 female

# THE BHF HEART FAILURE SPECIALIST NURSE

## Leicester

### Number of patients seen by nurse (in approximately 10-12 month)

Nurse	Enrolled	Not enrolled	Total	Mean No. Contacts (range)
1	10	62	72	7 (1-44)
2	17	28	45	6 (1-56)
3	27	68	95	7 (1-41)
<b>Total</b>	<b>54</b>	<b>158</b>	<b>212</b>	

### Readmissions and deaths by nurse (all cause)

Nurse	Enrolled		Not enrolled	
	Readmissions No. (%)	Deaths No. (%)	Readmissions No. (%)	Deaths No. (%)
1	8 (80)	3 (30)	16 (26)	16 (26)
2	3 (18)	2 (12)	7 (25)	6 (21)
3	9 (33)	1 (4)	18 (26)	5 (7)
<b>Total</b>	<b>20 (37)</b>	<b>6 (11)</b>	<b>41 (26)</b>	<b>27 (17)</b>

Overall readmission rate 29%, overall death rate 16%

### Heart Failure Classification of patients

NYHA	Enrolled	Not enrolled	Total	interviews
I	6	11	17	1
II	22	60	82	2
III	17	33	50	1
IV	6	18	24	1
Missing	3	36	39	

### Socio-demographics of patients

	Study Participants	Non -Participants
Median Age (Range)	74 (45-87)	Not Known
Ethnicity	91% white, 8% Asian, 1% Afro-Caribbean	90% white, 10% Asian
Alcohol abuse	current 2, former 1	current 1, former 11
Smoking	current 2, former 31	current 22, former 72
Overweight	14	51

### Medications at first visit (enrolled patients only)

	ACE	Beta Blocker
Yes	80%	67%

Interviews were with 5 patients: 4 white, 1 Asian; 3 male, 2 female

## Evaluation of the heart failure specialist nurse service

### Appendix 4 Patient treatment protocols

PATIENT MANAGEMENT						
CENTRE	HOME	Hosp OP CLINIC	GP/community clinic	Telephone follow-up	NURSE CONTACT available by mobile	Discharged from service?
BRADFORD	✓	no	proposed	✓	✓	Yes by 2 nurses no by 1
CAUSEWAY	✓ Risk Groups 3 & 4*	✓ HF Clinic Twice monthly	no	✓	✓	no
DUMFRIES	✓	✓	✓	✓	✓	no
LEICESTER	✓ 2 & then only if needed	no	no	✓	✓	no

\*Devised own Risk Profile – anyone in Risk Groups 3&4 automatically has a home visit

DRUG MANAGEMENT						
CENTRE	Titration in clinic	Titration at home	Nurse Supervised During titration	Titration as per protocol	Inform GP via letter	Inform GP via phone
BRADFORD	no	✓	no	✓	Letter faxed & some GPs need to be phoned	
CAUSEWAY	✓	no	✓ At HF Clinic pts stay 3 hrs to get obs monitored	✓	✓	✓
DUMFRIES	✓	✓	no	✓	Letter faxed & discussion by phone if nurse initiated.	
LEICESTER	no	✓	no	✓	Letter but some GPs require discussion first	

## Evaluation of the heart failure specialist nurse service

BLOOD MANAGEMENT				
CENTRE	Each visit	As per protocol	As per patient according to need	Prior to or after medication change
BRADFORD	U&Es on 1 <sup>st</sup> home visit;	✓	✓	✓
CAUSEWAY	U&Es at 1st visit unless just done in Hosp	✓	✓	After med or clinical changes by GP or nurse at home
DUMFRIES	U&Es at 1 <sup>st</sup> visit & according to need	When appropriate if symptomatic	✓	1 wk after med change
LEICESTER	U&Es at 1 <sup>st</sup> home visit unless current level known	✓	✓	Prior to and after med change

## Evaluation of the heart failure specialist nurse service

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