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Quality of Life and Quality of Care in Heart Failure: Perspectives of Irish Patients

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We hope the time and expertise entrusted to us by patients and health professionals in compiling this information will help with plans to improve heart failure management for Irish patients.
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Executive Summary

BACKGROUND
This research project contributes to a patient needs assessment in the development of the HSE National Heart Health Action Plan for Heart Failure. It provides the perspectives of heart failure patients on their quality of life and quality of care.

The project addresses the following questions:
1. What constitutes good quality of life for people in Ireland living with heart failure, and which factors are most important to them?
2. What is the quality of life currently experienced by people living with heart failure?
3. What are patients’ current experiences of heart failure health services in areas with and without specialised heart failure services?
4. What are patients’ views on what is important for good quality of care in heart failure services and how such services should be developed and delivered to optimise their quality of life?

METHODS
Two sources of Irish information were used to address these questions:

(i) An interview study of 98 Irish heart failure patients (consecutive outpatient clinic attendees), with comparison data on their status vis-à-vis others of their age from a large national survey of 1,033 community-dwelling older people. Heart failure patients were eligible for inclusion in the interview study if they had a primary diagnosis of heart failure (ejection fraction > 40%; diagnosis confirmed by echocardiogram). Interviews were conducted in 2005-6 within two weeks of a hospital outpatient department appointment.

(ii) A focus group study of 15 patients attending one of two heart failure rehabilitation programmes (one urban - Dublin, one rural - Wexford). Programmes were selected as exemplars of models of rehabilitation. Focus groups were completed in 2008.
RESULTS

• **Patient profile:** The heart failure patient interview group were on average aged 69 years, mostly men (83%) and married (77%). They had been diagnosed for an average of 5 years and almost half (47%) were classified as having NYHA class II heart failure.

• Patients reported loss of strength, breathlessness and fatigue as symptoms they experienced and attributed to their condition. Regarding health-related quality of life, patients experienced more physical than social limitations: 18% screened as depressed and 16% as anxious.

• Self-care varied by behaviour, with over 90% of patients reporting taking medication as prescribed but much fewer weighing themselves daily (14%), restricting fluid intake (39%) or reporting various signs of deterioration to their GP. Self-care behaviour was unrelated to length of time diagnosed or level of education.

• Patients made a similar number of visits to their GP as the general population group and most experienced no barrier to attending their GP. Patients expressed high levels of satisfaction with their GP.

• A quarter had visited Emergency Departments and 12% had attended in-patient hospital services in the previous year. This compares with 12% and 15% respectively in the general older population.

• Because the sample was sourced through hospital outpatient services, all participants had availed of outpatient services in the previous year. This compares with one fifth of the general population group. The majority were satisfied with the number of outpatient appointments they had received and had experienced no barrier to attending those services.

• In terms of service use overall, heart failure patients were thus similar in use of GP and in-patient care to an older Irish general population group but twice as likely to attend Emergency Departments and much more likely to attend outpatient services.

• Of concern, a follow-up of those interviewed found 24 of 98 (25%) had died within the subsequent year. The mortality rate was higher than anticipated and is a source of concern.

• **Management and Rehabilitation:** Findings from the interview study suggest poorer symptom recognition, monitoring and reporting in heart failure than is evident in other health conditions as seen in international findings. This indicates a need for targeted education. Patients need to recognise symptoms and exacerbations as evidence of their specific condition and
not merely as inevitable symptoms of ageing. Research shows that such education can reduce hospital readmissions and prevent acute heart failure exacerbations. This is best provided in structured management programmes that teach skills as well as imparting information.

- The focus group interviews highlighted the value to patients of structured rehabilitation programmes. The two projects identified were exemplars of a small but developing set of activities to promote structured chronic disease management for heart failure in Ireland.

- A key outcome for participants was the increased confidence and reassurance the programme provided. Following hospitalisation, many participants felt uncertain of the limits within which they could exercise to be both safe and to obtain cardiovascular benefit. The programme helped them to overcome their fears and follow advice to be active. Most participants felt ill-informed about their condition prior to attending the programme. The programmes addressed this and also counteracted a sense of isolation and loneliness as a heart failure patient.

- All focus group participants had completed the time-limited programmes. Some felt adrift once they had completed the programme and would welcome regular follow-up (‘booster sessions’) to maintain their focus.

- Participants felt that GPs played a minor part in managing their heart failure. The GP was not seen as the first point of contact if a heart failure medical need arose, with some participants not confident that the GP could deal adequately with the situation. Instead they reported they would contact the rehabilitation centre.

- Regarding hospital care, participants expressed frustration at the lack of continuity of personnel in their care – the heart failure programme contrasted with this experience of medical treatment. The opportunity to build a relationship with the rehabilitation team was undoubtedly an important aspect of the programme for participants.

IMPLICATIONS FOR SERVICE DEVELOPMENT

1. **Structured management:** With increasing numbers of heart failure patients, structured management programmes are needed to maximise self-care and promote effective coordinated use of primary and secondary care services. This will slow disease progression and minimise the numbers of emergency episodes of care needed in this chronic condition.

2. **Early detection and education:** Structured management begins with early detection of heart failure and education about heart failure. This needs to
include dimensions of self-care from lifestyle change to medication adherence to appropriate healthcare engagement.

3. **Heart failure programmes:** Patient education is best delivered in a programme of care addressing both knowledge and skills development. This includes addressing physical activity, dietary, smoking and other lifestyle issues. It also includes learning appropriate responses to signs and symptoms of heart failure or its exacerbations – in order to minimise clinical damage and/or emergency use of healthcare when with an earlier response it could be averted. Expertise in programme development is available through cardiac rehabilitation programmes in many centres and through existing exemplar projects that work specifically with heart failure groups in Ireland. Patients must be supported to develop physical activity routines that generalise beyond the equipment and structured routine of the formal rehabilitation setting.

4. **Shared care:** Models of shared care between hospital and primary care need to be established so that patients can be managed in primary care where appropriate. This will require investment in liaison of personnel between hospital and community to establish how rehabilitation and maintenance programmes can be delivered for the most effective and efficient management of heart failure. A hospital-only model is not likely to be sustainable. A community role needs to be established to make best use of the respective skills and resources of the specialist centre and the primary care team. Development of shared care needs to foster patient appreciation of the merits of such care.

5. **Audit:** Regarding programme development and needs, there is a dearth of information on the numbers of patients requiring management of heart failure and on the numbers currently included in rehabilitation programmes in Ireland. A National Heart Health Action Plan for Heart Failure needs such information as a benchmark for service development and later evaluation. An audit of patient numbers (those known in the hospital system in the first instance), patients currently receiving rehabilitation and the rehabilitation capacity of cardiac rehabilitation programmes to absorb additional patients should be undertaken. As a starting point, those newly identified as heart failure patients in hospital settings in 2010 could be quantified. Then the rehabilitation opportunities of these patients and the resources needed to provide rehabilitation could be assessed. This benchmark would provide both the opportunity to plan and to evaluate progress in the National Action Plan.
1. Introduction

This research project contributes to a patient needs assessment in the development of the National Heart Health Action Plan for Heart Failure 2008–2011. In developing the plan, it is important to have a good understanding of the perspectives of heart failure patients. The aim of this project was to provide information about the quality of life experienced by Irish patients living with heart failure, including their experience of healthcare and their views on the important components of heart failure services.

The project addresses the following questions:

1. What constitutes good quality of life for people in Ireland living with heart failure, and which factors are most important to them?
2. What is the quality of life currently experienced by people living with heart failure?
3. What are patients’ current experiences of heart failure health services in areas with and without specialised heart failure services?
4. What are patients’ views on what is important for good quality of care in heart failure services and how such services should be developed and delivered to optimise their quality of life?

Two sources of Irish information are used to address these questions:

(i) A study of 98 Irish heart failure patients (consecutive outpatient clinic attendees), with comparison data on their status vis-à-vis others of their age from a large national survey of 1,033 community-dwelling older people.

(ii) A focus group study of 15 patients attending one of two heart failure rehabilitation programmes (one urban, one rural).

The clinical and research background to the study is presented next.
2. Congestive Heart Failure

The World Health Organization (WHO) estimates that chronic diseases will be the leading cause of disability by 2020 and will be the most expensive problem faced by healthcare systems unless it is successfully managed (Whelan, 2002). The combined effects of an ageing population and advances in treatments for acute myocardial infarction have resulted in heart failure becoming what is known as a silent epidemic in industrialised nations. Heart failure is associated with severe symptom burden, functional limitation and premature death. Treatment regimens are complex and there are many barriers to adherence. Unsurprisingly, patients often report poor quality of life, high levels of psychological distress and difficulties adhering to treatment regimens.

Heart failure presents a diagnostic and management challenge, as most heart failure patients are older, have multiple co-morbidities and may be on multiple treatment regimens. In addition, the signs and symptoms of heart failure are non-specific, which can be a barrier to early diagnosis, essential in preventing disease progression and reducing hospitalisation. A further complication is that many patients are never told they have heart failure due to clinician reluctance to use the term. For instance, Clark and Lan (2004) found that a quarter of patients screened for a study were ineligible to take part because they did not know they had been diagnosed with heart failure.

Heart failure places significant burden on primary and secondary care services. It has been reported to use approximately 2–2.5% of the total healthcare budget in a number of countries (Stewart, Jenkins, Buchan et al., 2002). This proportion exceeds that used by HIV or cancer. A significant part of this cost is due to high hospital readmission rates. While hospitalisations for most other cardiovascular conditions have remained static or decreased over the past number of decades, hospitalisations for heart failure have increased three-fold (Masoudi, Rumsfeld, Havranek et al., 2004).

Treatment requires a complex combination of pharmacological and lifestyle interventions. Changes in lifestyle and symptom monitoring are important complementary strategies to pharmacological treatment. Lifestyle changes include the reduction of salt intake, fluid restriction, alcohol restriction and modifying physical activity. Symptom monitoring is essential to detect deterioration in the patient’s condition, e.g. increased shortness of breath, weight gain, oedema (fluid retention). It includes activities such as daily weighing to
monitor oedema. Taken together, these treatment regimes can be very demanding.

This report briefly summarises a number of key issues for the optimal care of heart failure patients and describes findings from a recent Irish study of heart failure patients (Morgan, 2008) to illustrate the current status of this group in Ireland. Key issues such as psychological well-being, adherence and self-care behaviour, quality of life and quality of health service care are discussed next.

2.1 Psychological well-being

Many heart failure patients report psychological problems, particularly depression and anxiety. Reported levels of depression vary greatly across studies. A recent review of 34 studies estimated the prevalence of depression as 30 to 55% (Johansson, Dahlstrom & Brostrom, 2006). A meta-analysis has also found that rehospitalisation, clinical events and general care use were higher among heart failure patients with depressive symptoms (Rutledge et al., 2006). However, there are concerns that depression is not routinely addressed in this group. The UK National Institute for Health and Clinical Excellence (NICE) 2003 guidelines state that the diagnosis of depression should be considered in all patients with heart failure, however evidence exists that treatment is not optimal for this group (Jacob, Sebastian & Abraham, 2003).

Assessment of depression in heart failure patients can be problematic as many of the physical signs of depression, such as fatigue and insomnia, are also primary symptoms of heart failure (MacMahon & Lip, 2002).

2.2 Adherence and self-care behaviour

Heart failure patients are required to follow complex medication regimens, make significant changes to their lifestyles and closely monitor their symptoms. Non-adherence has been reported to be a precursor of events leading to 64% of hospitalisations in the heart failure population (De Geest, Scheurweghs, Reynders et al., 2003). Adherence to medication regimens has been shown to be related to reduced mortality, for example, in the Candesartan in Heart Failure Assessment of Reduction in Mortality and Morbidity (CHARM) Programme (Granger, Swedberg, Ekman et al., 2005).
In the context of heart failure, studies have not only looked at overall medication adherence levels but also at patient knowledge of dosage and the correct timing of medications. One study found that 66% of patients knew the dose of their medication and 49% knew the correct time at which it should be taken (Hope, Wu, Tu, Young & Murray, 2004). In other studies, 50 to 87% of patients knew the correct dose and 64 to 88% the correct time of administration (Cline et al., 1999; German, Klein, McPhee & Smith, 1982; Michalsen et al., 1998).

Adherence to lifestyle changes poses even greater challenges for patients than adherence to medication regimens (Anderson, 1990). This is unsurprising given the increased effort required to make and sustain changes in key areas such as diet and physical activity.

In terms of diet, the low sodium diet is the cornerstone of non-pharmacologic therapy for heart failure (Hunt, Baker, Chin et al., 2001). However, non-adherence is common. A recent study which examined reasons for non-adherence found that the major reasons given were lack of knowledge, interference with socialisation and lack of food choices (Bentley, De Jong, Moser & Peden, 2005). It should be noted, however, that while lack of knowledge is often given as a reason for non-adherence to a low salt diet, a study by Ni and colleagues found that while 80% of heart failure patients knew they should limit their intake of salt, only one third avoided salty foods (Ni et al., 1999).

In conjunction with limiting salt intake, patients should also limit their fluid intake. Studies have shown that levels of adherence to this guideline vary from 70% among patients in primary care (Holst et al., 2007) to 33% among hospitalised patients (Stromberg, Martensson, Fridlund et al., 2003). The study by Ni and colleagues demonstrated a lack of understanding regarding fluid intake with 35% of participants endorsing the statement ‘you should drink lots of fluid’ and a further 19% giving a ‘don’t know’ response for the same item (Ni et al., 1999).

Heart failure has an illness trajectory which is characterised by periods of acute exacerbation and threats of hospitalisation and/or death. Symptom monitoring is a key part of preventing exacerbations or at least detecting changes early in order to enable early help seeking. Levels of fatigue, breathlessness and weight gain need to be carefully and frequently monitored. A study by De Geest and colleagues, however, found that 82% of patients showed knowledge deficits in
relation to heart failure symptoms (De Geest et al., 2003). In order to detect increasing weight, which may be an indication of congestion, it is recommended that patients weigh themselves daily (Baxter, 2005). This is one of the areas, however, where the adherence rates observed across studies have been particularly low. Reported rates of daily weight monitoring vary between 25 and 40% (Bushnell, 1992; Holst, Willenheimer, Martensson, Lindholm & Stromberg, 2007; Ni et al., 1999; Sulzbach-Hoke, Kagan & Craig, 1997). Reasons given for non-adherence include not having a scale, forgetfulness and not remembering being told (Sulzbach-Hoke et al., 1997).

The difficulties of adhering to a complex treatment regimen are understandable, and particularly so given that some treatments may have a negative impact on quality of life. For example, one patient’s view in a Scottish study: ‘one biggest nuisance is this water tablet...that really limits my movements...I can’t really go anywhere away from the house ...you see, I’ve got to know where every toilet is wherever I go’ (Murray et al., 2002).

To summarise, levels of adherence to treatment regimens among heart failure patients vary and are generally sub-optimal. Less is known about the factors which underpin and predict self-care behaviour. This is evidenced by the results of a recently updated Cochrane review which found that less than 50% of interventions tested in randomised trials improved adherence but that improvements were not sustained beyond 6 months (Haynes, Yao, Degani et al., 2005).

2.3 Quality of life

Quality of life (QoL) is a multidimensional concept that covers important areas or domains of a person’s life including physical functioning, psychological processes, social and economic concerns as well as spiritual and existential aspects (Davidson, Cockburn, Daly & Sanson Fisher, 2004). Studies have shown that health-related quality of life (HRQoL) is more severely impaired in heart failure than it is in several other common chronic conditions including diabetes, arthritis, chronic lung disease and angina (Jaarsma, 2002; Juenger, Schellberg, Kraemer et al., 2002; Stewart, Greenfield, Hays et al., 1989). This is unsurprising given the symptomatic burden of heart failure. Intrusive symptoms including dyspnoea, fatigue and oedema are common, and can be extremely distressing for patients. In a qualitative study by Murray and colleagues, one patient with advanced heart
failure stated ‘It’s a life but it’s not much of a life. I’m ready for the knacker’s yard’ (Murray et al., 2002, p. 931). Another described experiencing symptoms at night, saying ‘I was left sitting in a chair all night ... I would be screaming for air ... very, very frightening... I suppose it’s like drowning really’ (Murray et al., 2002, p. 931).

2.4 Health service use and quality of care

Understanding the experience and perspectives of heart failure patients is essential in developing better health services for them. Although patients may not always have the technical knowledge to judge the quality of their care (see Brown et al., 2003), there is growing recognition of the importance of their views, perspectives and preferences (Kane, Maciejewski & Finch, 1997; Nguyen Thi, Briançon, Empereur & Guillemin, 2002). Perceptions of healthcare quality have been found to have implications for health and well-being. In addition, information on quality of care is important in assisting policy development, in development and prioritisation of interventions and in the provision and management of health services.

Quality of care, including finding methods of optimising heart failure management in the community, will become ever more important in the Irish setting. Analyses of Hospital In-Patient Enquiry (HIPE) data prepared for the upcoming Cardiovascular Health Policy show that numbers of bed days in hospital for heart failure rose substantially from 1998 to 2006 (up to 280,195 days in 2006 (median stay 9 days) – a rise of 7.1% from 1998). More importantly, they accounted for 35% of in-patient stays and 41% of all bed days for cardiovascular diseases (the rest attributed to coronary heart disease, peripheral arterial disease, stroke and TIA). This increase in bed days is despite reducing episodes of care in 2006 (at 20,531 episodes – 7% less than 1998) and changing practices such that day cases have increased 67% to 2,090 in 2006.

Since the proportion of the population in older age groups has not changed substantially from 1998 to 2006 (and is very low, at 11%, by European standards), the concern is that this increase in bed use for heart failure could be greatly exaggerated in the coming decade, when the numbers of people aged 65 years and over are expected to increase by 41%. Hence innovations are needed in both preventive and treatment approaches for heart failure – such innovations will include much more proactive self-management of the condition and its exacerbations by patients. Initiatives which aim to achieve increased self-
management are needed, as is evaluation of the best methods of delivering effective methods. This report considers Irish heart failure patient profiles and patient perspectives to inform such developments.
3. Heart Failure: Irish Research Findings

The next section describes findings from a recent Irish longitudinal study of heart failure patients and compares these findings where possible with the findings from a study of equivalent community-dwelling older people. Both studies come from the Healthy Ageing Research Programme (HARP) and the findings relate to participants living in the Republic of Ireland.

The Healthy Ageing Research Programme (HARP) was a five-year project (2003-7) aiming to document ageing and health and their interaction with healthcare and social services in Ireland. Funded by the Health Research Board, it was a cross-institutional, cross-border project involving the Royal College of Surgeons in Ireland (RCSI), Trinity College Dublin (TCD) (Department of Gerontology), the Economic and Social Research Institute (ESRI) and the Queen’s University of Belfast (QUB) (Department of Geriatric Medicine). Institutional research leaders were Professor Hannah McGee (RCSI) (Principal Investigator), Professor Des O'Neill (TCD), Professor Richard Layte (ESRI) and Professor Bob Stout (QUB). The project involved studies with community-dwelling older people and those with serious chronic condition heart failure and stroke. Participants were included from the Republic and Northern Ireland, providing rich opportunity for comparison across healthcare systems (McGee et al, 2005). The data obtained provide a valuable opportunity to contribute to service planning for heart failure in Ireland.

3.1 Research populations

Heart failure: Heart failure patients were recruited from the outpatient departments of two large urban (Dublin) hospitals. Patients were eligible for inclusion in the study if they had a primary diagnosis of heart failure as determined by the hospital medical team (ejection fraction > 40%; diagnosis confirmed by echocardiogram); were not cognitively impaired (cognitive impairment was defined as scoring below the cut-off of 8 on the Abbreviate Mental Test (AMT) (Hodkinson, 1972)), and were able to complete the study through English. One hundred and ten potential participants were approached; 98 agreed to participate (response rate: 86%).

Older population: The older population sample comprised randomly selected, community-dwelling older people (N=1,053). Study inclusion criteria were age 65+ years, living in a private household and able to take part in a structured
interview. The Register of Electors was used as the most representative population sampling frame.

3.2 Procedures

3.2.1 Heart failure sample: The heart failure study was cross-sectional and participants completed questionnaires by interview. Within each hospital cardiologists provided consent to approach patients under their care. Interviews were conducted within two weeks of a hospital outpatient department appointment in 2005-6. Contact details for eligible patients attending a routine outpatient appointment were forwarded by the medical team. Where feasible, following informed consent, interviews were carried out in the hospital. Some interviews were conducted in patients’ homes.

3.2.2 Older population sample: This was a cross-sectional, face-to-face interview study. Participants were interviewed in their own homes in 2004. Randomly selected household addresses were visited, and when a person aged 65 or more was resident, he/she was asked to participate. Where more than one person over 65 was resident, the individual whose birthday was closest to the interview date was asked to participate in a home interview. A sample of 1,053 people (age range 65–102 years) participated (68% participation rate).

3.2.3 Procedures and measures: The studies received ethical approval from the relevant institutional (general population study) and hospital (patient study) ethics committees. Instruments assessing physical capacity, depression, quality of life, self-care behaviour, health service use and quality of care evaluations were included, as described next.

3.2.4 Physical capacity: The heart failure study included a measure of function – the Duke Activity Status Index (DASI), a simple, self-administered, 12-question measure of daily living activities developed by Hlatky and colleagues (Hlatky et al., 1989). Questions take less than five minutes to complete (Carter, Holiday, Grothues et al., 2002) and relate to personal care, ambulation, household tasks, sexual function and recreation. The questions aim to establish the amount of difficulty patients experience in performing these activities. Items are weighted, reflecting the amount of effort involved. Possible scores range from 0 to 58.2 with higher scores reflecting better physical functioning and a score of zero reflecting an inability to perform any basic activities of daily living (Hlatky et al., 1989). The
DASI is a practical tool which has demonstrated good sensitivity, validity and reliability in the context of heart failure (Nelson, Herndon, Mark et al., 1991) and other cardiovascular conditions (Bairey Merz, Olson, McGorray et al., 2000). In the current study the DASI is used as an assessment of functional impairment/functional limitation.

3.2.5 Psychological well-being: Psychological well-being was assessed using the HADS (Zigmond & Snaith, 1983). This scale is a well-established and widely used self-rating instrument originally designed as a screening measure to indicate the presence of possible and probable anxiety and depression in non-psychiatric patients attending hospital clinics. The HADS is a brief 14-item, self-report measure with two subscales (a 7-item anxiety subscale (HADS-A) and a 7-item depression subscale (HADS-D)). All items are rated on a 4-point scale representing the degree of distress experienced during the preceding week. Completion takes between two and six minutes. Anxiety and depression items are scored separately. Each item is scored from 0-3 thereby giving each subscale a range of possible total scores from 0 to 21. For each subscale, a score of 7 or lower indicates ‘non-case’; a score of 8-10 indicates ‘doubtful case/possible clinical disorder’; and a score of 11 or higher indicates ‘probable/definite case’ of either anxiety or depression.

3.2.6 Illness perceptions: Illness perceptions were assessed using the identity and cause components of the IPQ-R (Moss-Morris et al., 2002). This measure is a well-validated and widely used quantitative measure of the five components of illness outlined in Leventhal’s self-regulatory model (Leventhal et al., 1984) and has been successful in predicting different aspects of adaptation in chronic illness (Moss-Morris et al., 2002). The components are identity, consequences, timeline, control/cure and cause.

The identity scale consists of a list of 12 symptoms (e.g. headache, fatigue). Patients are asked to state if they have experienced each symptom since their illness and if so, whether it was caused by their illness. The number of the ‘yes’ rated items endorsed on this scale forms the patient’s identity score. The cause scale is presented as a list of factors (e.g. pollution, bad luck, stress). Patients are asked to indicate the extent to which they agree or disagree that each factor is a possible cause of their illness, using a 5-point Likert scale. Patients are then asked to list, in rank order, the three most important factors they believe caused
their illness. For each scale scores are summed and divided by the number of items in the scale, giving a total score range of 1-5.

### 3.2.7 Quality of life:
QoL was assessed using the Kansas City Cardiomyopathy Questionnaire (KCCQ) - a 23-item, condition-specific health status measure which assesses HRQoL in heart failure patients regardless of aetiology (Green et al., 2000). Each item has a 5-, 6- or 7-point Likert scale. The measure includes a number of subscales that quantify symptoms and symptom stability, physical limitation, social limitation, self-efficacy and quality of life (Spertus, Tooley, Jones et al., 2002). A total scale score (which reflects overall health status for a patient with heart failure), as well as eight subscale scores can be calculated. The scales are scored from 0-100, with higher scores representing fewer symptoms and better functioning. A change of 5 points in the KCCQ total score is considered clinically significant (Rumsfeld et al., 2003).

The KCCQ has been reported to be a valid and reliable measure for use with heart failure patients (Dekerlegand, 2005; Green et al., 2000) including heart failure outpatients (Soto, Jones, Weintraub, Krumholz & Spertus, 2004). The responsiveness and clinical sensitivity of the KCCQ have also been confirmed by more recent studies (Bennett, Oldridge, Eckert et al., 2002; Eurich, Johnson, Reid & Spertus, 2006; Hauptman, Masoudi, Weintraub et al., 2004; Thweatt, Aron, Coles-Herman et al., 2004).

### 3.2.8 Self-care behaviour:
Self-care behaviour was assessed using the European Heart Failure Self-Care Behaviour Scale (EHFSCBS: Jaarsma et al., 2003). This scale is a 12-item, self-administered questionnaire concerning the self-care behaviour of heart failure patients. Each item takes the form of a statement e.g. ‘I weigh myself every day’, ‘I exercise regularly’, and ‘I eat a low salt diet’. Respondents are asked to indicate their level of agreement with each statement on a 5-point scale ranging from 1 (‘I completely agree’) to 5 (‘I don’t agree at all’). Total scale scores range from 12 to 60. The EHFSCBS has been found to be a valid, reliable and practical scale for measuring the self-reported self-care of heart failure patients (Jaarsma et al., 2003).

### 3.2.9 Health service use:
Health service use was assessed using single-item indicators which determined how often respondents availed of GP services in the past year and whether they had used hospital services in the past year. They were also asked whether anything had prevented them from accessing those
services. Responses to this question were ‘Transportation’, ‘Cost’, ‘It takes too much time’, ‘It’s too much hassle’, ‘It’s not helpful’, ‘Too ill’, ‘Other’ (to be specified by the respondent), and ‘Nothing prevents me’. Respondents were asked whether cost had prevented them from attending their GP or filling a prescription. The responses to both these questions were ‘Yes often’, ‘Occasionally’, ‘No’, ‘Not sure’, and ‘Not applicable’.

In relation to use of hospital services, respondents were asked to identify the number of times they had attended accident and emergency (A&E), scheduled inpatient and scheduled outpatient services. Respondents were also asked whether they were satisfied with the number of outpatient appointments they had received.

3.2.10 Quality of care assessment: Satisfaction with the quality of care provided by GP services was assessed using 11 statements, such as ‘I am satisfied that my concerns are taken seriously by my GP’ and ‘My GP is not very good at explaining my health problems’. Participants indicated their level of agreement with the statements on a 5-point scale ranging from ‘Strongly agree’ to ‘Strongly disagree’. 
4. Results

4.1 Participant characteristics
Demographic and clinical profiles are presented in Table 1. The heart failure sample was somewhat younger, almost twice as likely to be male and was much more likely to be married than the general population group.

<table>
<thead>
<tr>
<th>Socio-demographic &amp; clinical characteristics</th>
<th>HARP: General population sample (age 65+)</th>
<th>HARP: Heart failure sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years) (SD)</td>
<td>74.0 (6.8)</td>
<td>69.4 (8.8)</td>
</tr>
<tr>
<td>Age 65+ years (%)</td>
<td>100</td>
<td>75</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Men (%)</td>
<td>44</td>
<td>83</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married (%)</td>
<td>54</td>
<td>77</td>
</tr>
<tr>
<td>Separated/Divorced (%)</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Widowed (%)</td>
<td>37</td>
<td>15</td>
</tr>
<tr>
<td>Never married (%)</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>NYHA status (heart failure sample only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Class I (%)</td>
<td>n/a</td>
<td>28</td>
</tr>
<tr>
<td>Class II (%)</td>
<td>n/a</td>
<td>47</td>
</tr>
<tr>
<td>Class III (%)</td>
<td>n/a</td>
<td>18</td>
</tr>
<tr>
<td>Class IV (%)</td>
<td>n/a</td>
<td>8</td>
</tr>
</tbody>
</table>

The majority of patients were assessed as having NYHA class II heart failure.

4.2 Heart failure severity, years diagnosed and functional impairment
Patients had been diagnosed for an average of 4.7 years (range: 1 – 15; SD = 3.7). Fifty-one percent had been diagnosed for between one and three years, 20% for between four and six years and 29% for seven or more years.
The mean scores on the DASI indicated a moderate level of functional impairment (Table 2).

### Table 2  Levels of functional impairment on the Duke Activity Status Index (DASI)

<table>
<thead>
<tr>
<th>Items</th>
<th>Mean (SD)</th>
<th>Median (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DASI</td>
<td>22.8 (12.1)</td>
<td>23.5 (0.0 – 58.2)</td>
</tr>
</tbody>
</table>

#### 4.3 Illness perceptions

In terms of how patients felt about their illness, their responses indicated that they believed their illness was more chronic or long-term than acute or short-term in nature \( (M = 3.9; SD = 0.7) \) and more cyclical (i.e. having a course that includes periods of symptom stability and exacerbations) than constant \( (M = 2.8; SD = 0.9) \). Patients felt that their illness could be controlled both personally \( (M = 3.4; SD = 0.6) \) and with medical treatment \( (M = 3.3; SD = 0.5) \). Patients had a clear picture of their illness \( (M = 3.5; SD = 0.7) \) and the mean score on the emotional representations subscale indicated that patients reported neutral feelings about their illness \( (M = 3.0; SD = 0.8) \).

The identity component of the IPQ-R is concerned with the degree to which patients endorse symptoms experienced as being caused by their illness (in this case heart failure). Table 3 outlines the percentage of patients who reported experiencing a given symptom since they became ill, and the percentage who indicated that they believed this symptom to be caused by their illness. Loss of strength, breathlessness and fatigue were highly endorsed as being illness related.
### Table 3: IPQ-R identity subscale: Percentage of patients endorsing symptoms experienced as being caused by heart failure

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% experienced symptom</th>
<th>% attributing symptom to HF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathlessness</td>
<td>79</td>
<td>75</td>
</tr>
<tr>
<td>Fatigue</td>
<td>79</td>
<td>68</td>
</tr>
<tr>
<td>Loss of strength</td>
<td>74</td>
<td>65</td>
</tr>
<tr>
<td>Sleep difficulties</td>
<td>57</td>
<td>47</td>
</tr>
<tr>
<td>Stiff joints</td>
<td>55</td>
<td>45</td>
</tr>
<tr>
<td>Dizziness</td>
<td>37</td>
<td>35</td>
</tr>
<tr>
<td>Wheeziness</td>
<td>35</td>
<td>29</td>
</tr>
<tr>
<td>Pain</td>
<td>33</td>
<td>35</td>
</tr>
<tr>
<td>Weight loss</td>
<td>27</td>
<td>14</td>
</tr>
<tr>
<td>Nausea</td>
<td>26</td>
<td>22</td>
</tr>
<tr>
<td>Upset stomach</td>
<td>22</td>
<td>34</td>
</tr>
<tr>
<td>Sore eyes</td>
<td>21</td>
<td>12</td>
</tr>
<tr>
<td>Headaches</td>
<td>17</td>
<td>15</td>
</tr>
<tr>
<td>Sore throat</td>
<td>12</td>
<td>9</td>
</tr>
</tbody>
</table>

HF: heart failure

The cause component of the IPQ-R is concerned with whether or not patients attribute their own illness to certain causes. The percentage of patients who indicated that they agreed or strongly agreed that a given cause may be applicable in their case is outlined in Table 4.
Table 4  Patients’ causal attributions for illness

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% agree/ strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hereditary – it runs in my family</td>
<td>52</td>
</tr>
<tr>
<td>Stress or worry</td>
<td>42</td>
</tr>
<tr>
<td>Ageing</td>
<td>37</td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td>28</td>
</tr>
<tr>
<td>Your own behaviour</td>
<td>26</td>
</tr>
<tr>
<td>Smoking</td>
<td>23</td>
</tr>
<tr>
<td>Overwork</td>
<td>20</td>
</tr>
<tr>
<td>Diet or eating habits</td>
<td>19</td>
</tr>
<tr>
<td>Alcohol</td>
<td>17</td>
</tr>
<tr>
<td>My emotional state e.g. feeling down, lonely, anxious, empty</td>
<td>11</td>
</tr>
<tr>
<td>Your personality</td>
<td>9</td>
</tr>
<tr>
<td>A germ or virus</td>
<td>8</td>
</tr>
<tr>
<td>Poor medical care in the past</td>
<td>7</td>
</tr>
<tr>
<td>Altered immunity</td>
<td>4</td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td>2</td>
</tr>
<tr>
<td>Your mental attitude e.g. thinking about life negatively</td>
<td>2</td>
</tr>
<tr>
<td>Family problems or worries caused my illness</td>
<td>2</td>
</tr>
<tr>
<td>Accident or injury</td>
<td>2</td>
</tr>
</tbody>
</table>

Approximately half of the heart failure patients indicated that heredity was a cause of their illness. Stress or worry and ageing were also seen as important causal factors by patients.

4.4 Quality of life

The scores on the KCCQ subscales indicated that patients were experiencing more physical than social limitations due to their illness.

Perhaps surprisingly, there was no difference in QoL scores between younger and older patients ($r = -.052; p = .256$). Disease severity was negatively correlated with QoL scores ($r = .257; p < .001$), with higher NYHA classification associated with lower QoL scores.
4.5 Psychological well-being

HADS scores were categorised as being in the range for ‘non-case’ of anxiety/depression, indicating a ‘doubtful/possible’ case of anxiety/depression or indicating a ‘probable/definite’ case of anxiety/depression (see Figure 1 below).1

<table>
<thead>
<tr>
<th>Depression</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-case</td>
<td>63%</td>
</tr>
<tr>
<td>Doubtful/possible</td>
<td>19%</td>
</tr>
<tr>
<td>Probable/definite</td>
<td>18%</td>
</tr>
</tbody>
</table>

**Figure 1** Depression and anxiety (HADS) scores (n = 98)

Eighteen per cent of patients had HADS-D scores which indicated ‘probable/definite’ clinical depression while 18% had HADS-A scores indicating ‘probable/definite’ anxiety disorder.

There was a negative correlation between DASI scores (functional status) and scores on both the HADS-A and HADS-D. Lower DASI scores (indicating more functional impairment) were associated with higher anxiety and depression scores (indicating increased psychological distress).

4.6 Self-care behaviour

The percentage of patients who indicated that they adhered to the behaviours on the European Heart Failure Self-Care Behaviour Scale varied considerably according to the behaviour in question (Figure 2).2

---

1 A score of 7 or lower indicates ‘non-case’; a score of 8-10 indicates ‘doubtful case/possible clinical disorder’; and a score of 11 or higher indicates ‘probable/definite case’ of either anxiety or depression.
Self-reported medication adherence was high (90% +). The lowest levels of adherence were observed in relation to daily weighing, contacting a doctor/nurse in the event of weight gain and taking regular exercise.

![Self-care behaviour, n=98]

**Figure 2**  Patient adherence by item on the EHFSCBS (n = 98)

A one-way between-groups ANOVA was used to explore the impact of level of education (3 levels) on self-care behaviour. No significant difference between the mean self-care behaviour scores was found ($F (5,155) = .778, p = .567$). Thus self-care did not vary by education. Similarly, there was no link between length of time diagnosed and self-care behaviour.

---

2 Calculated as percentage of patients scoring 1 or 2 on the 5-point scales starting at 1 (‘I completely agree’).
5. Use of Services

5.1. GP services

5.1.1 Use of GP services

The mean number of visits to a GP in the previous year by heart failure patients was 4.2 ($SD = 3.5$; median = 4.0; range = 0–18). Over half made 4 or more visits, while nearly one-third made between 1 and 3 visits; 16% had not visited their GP in the previous year (see Table 5). (Note that appointments were not necessarily related to the participants’ heart failure.) Heart failure patients had the same median number of GP visits as the general population group (4 visits). The mean number of visits to a GP in the previous year for general population was 5 ($SD = 5.4$; median = 4.0; range = 0–84). In this group, 5% had not visited their GPs; 37% had had between 1 and three, while 58% had had 4 or more visits.

<table>
<thead>
<tr>
<th>No. of GP visits</th>
<th>General population (N = 1,025) (%)</th>
<th>Heart failure sample (N = 98) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>1-3</td>
<td>37</td>
<td>32</td>
</tr>
<tr>
<td>≥ 4</td>
<td>58</td>
<td>52</td>
</tr>
</tbody>
</table>

For heart failure patients, the mean number of visits to the GP increased with increases in NYHA status – from 3.3 visits (class 1) to 4.9 visits (class III) – while for those at class IV, GP attendance was lower at 2.6 visits in the last year (Table 6).

<table>
<thead>
<tr>
<th>NYHA status (N = 98)</th>
<th>Class I</th>
<th>Class II</th>
<th>Class III</th>
<th>Class IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP visits</td>
<td>Mean</td>
<td>Median</td>
<td>SD</td>
<td>Range</td>
</tr>
<tr>
<td></td>
<td>3.3</td>
<td>4</td>
<td>2.7</td>
<td>0-9</td>
</tr>
<tr>
<td></td>
<td>4.7</td>
<td>4</td>
<td>4.0</td>
<td>0-18</td>
</tr>
<tr>
<td></td>
<td>4.9</td>
<td>4</td>
<td>3.7</td>
<td>0-12</td>
</tr>
<tr>
<td></td>
<td>2.6</td>
<td>2.5</td>
<td>2.0</td>
<td>0-6</td>
</tr>
</tbody>
</table>
Many patients reported that they saw their GP infrequently but had regular hospital outpatient visits. This is reflected in the next section where few barriers to accessing GP care were identified.

### 5.1.2 Barriers to using GP services

Most respondents experienced no barrier to attending their GP in the past year (heart failure: 87%; general population: 97%). The most common barrier identified by the heart failure sample was being too ill, cited by 9%. The only other barrier for this group was transportation, cited by 4%. Cost did not prevent any from seeing their GP or from filling out a prescription. Hardly any of the general population sample reported that cost or transportation problems had prevented them from going to their GP (1% for both).

### 5.1.3 Satisfaction with GP

In general, participants expressed high levels of satisfaction with their GP (Table 7). For example, 81% of the heart failure sample felt that their GP had explained their health problems well to them, and the same number felt that they received feedback on the progress of their condition. This compares with 75% and 83% respectively for those statements when put to the general population sample. The main area of dissatisfaction for heart failure patients was access to appointments, where 15% either disagreed or disagreed strongly that it was easy to get an appointment at the time they wanted; the corresponding figure for the general population was 8%. Catering for the needs of patients was also an area of greater dissatisfaction for heart failure patients, with 66% agreeing that the surgery catered well for patients’ needs; the figure for the general population was 78%.
Table 7  Satisfaction with GP by heart failure and general older population samples†

<table>
<thead>
<tr>
<th>Perception</th>
<th>Strongly agree (%)</th>
<th>Agree (%)</th>
<th>Neither agree nor disagree (%)</th>
<th>Disagree (%)</th>
<th>Strongly disagree (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’m satisfied that my concerns are taken seriously by the GP*</td>
<td>0 (37)</td>
<td>85 (55)</td>
<td>12 (5)</td>
<td>3 (3)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>My GP sees older people as being a high priority group*</td>
<td>0 (6)</td>
<td>80 (43)</td>
<td>16 (38)</td>
<td>4 (11)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>My GP is not very good at explaining my health problems*</td>
<td>0 (3)</td>
<td>4 (15)</td>
<td>15 (8)</td>
<td>81 (60)</td>
<td>0 (15)</td>
</tr>
<tr>
<td>My GP gives me feedback on the progress of my condition*</td>
<td>0 (15)</td>
<td>81 (68)</td>
<td>14 (10)</td>
<td>5 (6)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>My GP’s surgery caters well for the needs of patients e.g. wheelchair access*</td>
<td>0 (14)</td>
<td>66 (62)</td>
<td>22 (14)</td>
<td>9 (9)</td>
<td>3 (1)</td>
</tr>
<tr>
<td>It is generally easy to get an appointment at the time I want*</td>
<td>0 (16)</td>
<td>73 (69)</td>
<td>12 (8)</td>
<td>12 (6)</td>
<td>3 (2)</td>
</tr>
<tr>
<td>I am satisfied that information is given to me by my GP in a sensitive and reassuring way*</td>
<td>0 (41)</td>
<td>87 (53)</td>
<td>9 (4)</td>
<td>4 (2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>I am satisfied with the quantity of information received from my GP about my health*</td>
<td>0 (33)</td>
<td>88 (57)</td>
<td>12 (6)</td>
<td>0 (4)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>After I see my GP I feel my problems are understood*</td>
<td>0 (17)</td>
<td>89 (69)</td>
<td>11 (11)</td>
<td>0 (3)</td>
<td>0 (1)</td>
</tr>
<tr>
<td>In my GP’s surgery, information given to reception staff remains confidential*</td>
<td>0 (21)</td>
<td>90 (70)</td>
<td>10 (9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

† Some figures do not add up to 100% due to rounding
* General population percentages in brackets
5.2 Hospital services

5.2.1 Attendance at hospital
As heart failure participants were identified for this study through outpatient clinic attendance, by definition all participants had attended a hospital for medical treatment in the previous year. Of the general population sample, 37% had visited a hospital for medical treatment.

5.2.2 Emergency Department visits
A quarter of the participants in the heart failure study attended Emergency Departments (EDs) in the last year. The majority made 1 visit with a range of 1 to 4 visits (Table 8). In the general population, 10% had attended EDs in the previous year, the majority also attending once.

Table 8  Visits to Emergency Departments in the last year

<table>
<thead>
<tr>
<th>No. of visits</th>
<th>General population (N = 1,053) (%)†</th>
<th>Heart failure sample (N = 98) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>88</td>
<td>75</td>
</tr>
<tr>
<td>1</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

† 2% of the general population were unable to provide a figure

In terms of NYHA class, class IV patients visited EDs less than patients in the other classes, and those who did attend EDs visited once. Patients who visited three or more times were mostly in class III. Class I patients visited EDs no more than twice. Table 9 provides more details on the breakdown of ED visits by NYHA status.
Table 9  Profile of Emergency Department visits by patient NYHA status

<table>
<thead>
<tr>
<th>NYHA status (N = 98)</th>
<th>No. of visits</th>
<th>Class I (%)</th>
<th>Class II (%)</th>
<th>Class III (%)</th>
<th>Class IV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class I</td>
<td>70</td>
<td>76</td>
<td>71</td>
<td>88</td>
<td></td>
</tr>
<tr>
<td>Class II</td>
<td>22</td>
<td>14</td>
<td>14</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Class III</td>
<td>7</td>
<td>8</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Class IV</td>
<td>0</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

† Some figures do not add up to 100% due to rounding

5.2.3 In-patient visits

Twelve per cent of the heart failure sample availed of in-patient services in the previous year, and all of these had one stay. The number of days participants spent as in-patients was not documented, so it is not possible to distinguish between long and short stays. In the general population, 15% had attended in-patient services in the previous year; of these, the majority were admitted once (8% of the total sample).

Table 10 shows the use of in-patient services among heart failure patients by NYHA status. The highest percentage of in-patient service users were in class III.

Table 10  Profile of in-patient visits by heart failure patients by NYHA status

<table>
<thead>
<tr>
<th>NYHA status (N = 98)</th>
<th>No. of visits</th>
<th>Class I (%)</th>
<th>Class II (%)</th>
<th>Class III (%)</th>
<th>Class IV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Class I</td>
<td>93</td>
<td>88</td>
<td>79</td>
<td>88</td>
<td></td>
</tr>
<tr>
<td>Class II</td>
<td>7</td>
<td>12</td>
<td>21</td>
<td>12</td>
<td></td>
</tr>
</tbody>
</table>

5.2.4 Outpatient services

As the heart failure sample was sourced through hospital outpatient services, all participants in that study had availed of outpatient services in the previous year. The mean number of visits was 5.3 (SD = 3.8; median = 4; range = 1–18). Forty-five per cent made between 1 and 3 visits; another 45% made between 4 and 10 visits; and 10% made more than 10 visits (Table 11). In the general population sample, 20% had visited outpatients in the previous year. The mean number of visits by this group was 3.7 (SD = 7.1; median = 2; range = 1–78), and the majority (11% of the total sample) made between 1 and 3 visits.
Table 11  Visits to outpatient services†

<table>
<thead>
<tr>
<th>No. of visits</th>
<th>General population (N = 1,053) (%)</th>
<th>Heart failure sample (N = 98) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>80</td>
<td>0</td>
</tr>
<tr>
<td>1–3</td>
<td>11</td>
<td>45</td>
</tr>
<tr>
<td>4–10</td>
<td>3</td>
<td>45</td>
</tr>
<tr>
<td>&gt;10</td>
<td>1</td>
<td>10</td>
</tr>
</tbody>
</table>

† 5% of the general population were unable to provide a figure

Table 12 shows use of outpatient services by heart failure patients by NYHA status. In general, patients in higher NYHA groups had more visits. Half or more in each group had 4 or more appointments in the year.

Table 12  Profile of outpatient visits by heart failure patients by NYHA status

<table>
<thead>
<tr>
<th>NYHA status (N=98)</th>
<th>No. of visits</th>
<th>Class I (%)</th>
<th>Class II (%)</th>
<th>Class III (%)</th>
<th>Class IV (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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5.2.5 Adequacy of outpatient services

Most participants (heart failure: 95%; community sample: 91%) were satisfied with the number of outpatient appointments they had received. Just 2% of heart failure patients had not been able to get an appointment and 3% reported that they had had too many appointments. None of the general population sample reported either of these problems. However, 9% believed they did not have appointments frequently enough.

5.2.6 Barriers to attendance at outpatient services

Most respondents (heart failure: 93%; community sample: 99%) experienced no barrier to attending outpatient services. The most likely obstacle for heart failure patients was being too ill to attend. Transportation proved to be an issue for 2% of the heart failure sample.
5.3 Summary

- The heart failure patient group were on average 69 years old; mostly men (83%) and married (77%). They had been diagnosed for an average 4.9 years; almost half (47%) were classified as NYHA class II heart failure.
- Patients reported loss of strength, breathlessness and fatigue as symptoms they experienced and attributed to their heart condition. Almost half agreed that heredity was a cause of their illness. Stress or worry, ageing and chance were also endorsed as being likely causes.
- Regarding health-related quality of life, patients experienced more physical than social limitations due to their ill-health, with older patients experiencing more physical limitation and increased symptom severity.
- Regarding psychological well-being, 18% of patients were identified as having ‘probable/definite’ depression and 16% ‘probable/definite’ anxiety. Higher levels of psychological distress were associated with higher functional impairment.
- Self-care varied by behaviour, with over 90% of patients reporting taking medication as prescribed but much fewer weighing themselves daily (14%), restricting fluid intake (39%) or reporting various signs of deterioration to their GP. Self-care behaviour was unrelated to length of time diagnosed or level of education.
- Patients made a similar number of visits to their GP as the general population group and most experienced no barrier to attending their GP. The most common barrier reported was being too ill. In general, patients expressed high levels of satisfaction with their GP.
- A quarter of patients had visited Emergency Departments and 12% had attended in-patient hospital services in the previous year. This compares with 12% and 15% respectively in the general population.
- Because the sample was sourced through hospital outpatient services, all participants had availed of outpatient services in the previous year. This compares with one-fifth of the general population group. The great majority were satisfied with the number of outpatient appointments they had received and had experienced no barrier to attending those services.
- In terms of service use overall, heart failure patients were thus similar in use of GP and in-patient care to an older general population group but twice as likely to attend Emergency Departments and much more likely to attend outpatient services (it is difficult to be precise on this comparison as the heart failure sample was recruited through an outpatient attendance system so it is not clear how many such patients would not attend in a year).
6. Discussion – Key Points

6.1 Sample profile: Patients had been diagnosed for an average of almost five years. Almost half had been diagnosed for less than six years and were medically assessed as having NYHA class II heart failure. Patients with this class of heart failure have cardiac disease resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea or anginal pain (Criteria Committee of the New York Heart Association, 1994). It is notable that while the study had a higher proportion of NYHA class II patients than the estimated average of 35% in heart failure populations (Heart Failure Health Centre, 2008), the proportion of patients in NYHA class IV was equal to the heart failure population estimate (5%). Patients in this group are often excluded from randomised clinical trials and are difficult to recruit in community or OPD based studies, due to the severity of their illness.

6.2 Illness perceptions: Regarding patient perceptions of illness, patient scores on the illness identity subscale reflected the fact that many heart failure symptoms are vague and non-specific. In the case of other illnesses, symptoms may be more obviously disease-related and so there may be less ambiguity with regard to their cause.

6.3 Self-care: Self-care behaviour varied by activity. While in excess of 90% of patients indicated that they took their medication as prescribed, on the other extreme the percentage of patients who reported weighing themselves daily was low (14%). Symptom reporting levels were also low, which is consistent with research reporting delays in help-seeking among heart failure patients. Evangelista and colleagues, for example, have reported that heart failure patients seek advice later than patients with chest pain (Evangelista et al., 2000). No associations between self-care behaviour scores and level of education or length of time diagnosed were identified.

6.4 Psychological well-being (anxiety and depression): Levels of ‘probable/definite’ depression and anxiety were 18% and 16% respectively, with 19% and 29% in the ‘possible/doubtful’ category. With regard to depression, the current study figures are slightly less than that reported in the 2006 meta-analysis conducted by Rutledge and colleagues. They found that clinically significant depression was present in 21.5% of heart failure patients (Rutledge et al., 2006). Levels of ‘probable/definite’ anxiety were lower than those estimated
in previous research; however, the high percentage of ‘possible/doubtful’ cases should be considered. Rutledge and colleagues found that anxiety and depression scores were positively correlated with NYHA classification, a finding that was replicated in this study. As well as being associated with increased severity, higher depression and anxiety scores were also associated with increased functional limitation.

6.5 Quality of life: Patient scores indicated more physical than social limitations were imposed by their illness. Higher NYHA class was associated with poorer QoL scores. Clinical summary scores were poorer for older patients. No age or gender differences were observed. Patients in the current study had poorer scores on all KCCQ subscales, except self-efficacy, than those reported by Faller and colleagues who also assessed QoL in heart failure outpatients (Faller, Stork, Schowalter et al., 2007). This may be a reflection of the higher average age of patients in the current study. No other studies could be identified to provide an alternative comparison.

6.6 Study implications: An important finding of the current study is that the mean identity scores of heart failure patients are lower those of other chronically ill patient groups. This may have important implications in terms of symptom recognition and monitoring. In a study of elderly heart failure patients, Friedman (1997) found that dyspnoea began an average of 3 days before hospitalisation and that oedema, cough, fatigue and weight gain were present on average a week before admission. The author suggests that these patients evaluated their symptoms as non-acute and non-specific, delaying help seeking until the situation became more serious. Evangelista and colleagues also reported delays in contacting a hospital among heart failure patients (Evangelista et al., 2000). They found that patients with dyspnoea and oedema, in particular, had delay times twice as long as those who did not have these symptoms. These symptoms may progress slowly. The slow rate of progression of symptoms has been found to be an important factor in determining help seeking in other patient groups, for instance in AMI, where it has been found to be the strongest predictor of delay (Schmidt & Borsch, 1990).

Addressing the issues of symptom recognition, monitoring and reporting is therefore important. A randomised controlled clinical trial of 223 hospitalised patients found that a single hour of individualised education delivered in a one-on-one session with a nurse before discharge improved self-care (low-salt diet,
fluid restriction, recording daily weights, performing regular exercise and monitoring symptom changes) and cut by one-third (35%) the patient’s risk of returning to the hospital or dying over the following 6-month period. The education session included information on what heart failure is, how it is caused, the major symptoms, the main measures of heart-pumping capacity, the drugs used in treatment, why there are so many, how they work, their benefits and side effects, and what lifestyle changes and habits can help improve life for patients. Specific information relating to daily salt/sodium intake limits, daily fluid intake, daily weighing and why all are important was given and patients were counselled to make plans of action for what to do if symptoms worsened (Koelling, Johnson, Cody & Aaronson, 2005). Other focused interventions have also yielded successful results, for example, a randomized controlled trial of the effectiveness of telephone counselling by a pharmacist was shown to improve adherence and reduce mortality (Wu, Leung, Chang et al., 2006).

The success of interventions such as those mentioned highlights the need for health service providers to consider how such programmes can potentially reduce hospital readmissions and prevent acute heart failure exacerbations. It also points to the importance of considering how investment in support services and management programmes can be most effectively and efficiently incorporated into the service structures of individual health systems.

The success of the intervention described above also reinforces the general rule that where behavioural change is the goal, programmes that teach skills and actively consider how they can be applied in the patient’s world are more likely to be effective than those that provide didactic information only (Bennett, 2004). Implementing successful intervention programmes involves achieving a balance between reaching the maximum number of patients and also being effective on an individual level. Interventions which are grounded in theory and can be replicated across different settings are therefore invaluable.

A potential limitation of this study is that the proportion of women in the sample was low (approximately 20%) thus limiting the generalising of results. Randomised trials tend to report proportions between 0 – 33% (McMurray, 2000; Moser, 1997). Community based studies are more successful at recruiting female participants, for example, 47% of the participants enrolled in the EuroHeart Failure survey programme were women (Cleland et al., 2003). Only patients with an ejection fraction of less than 40% were considered eligible for inclusion in the
present study. Studies have indicated that patients with such left ventricular systolic dysfunction (LVSD) are more likely to be young and male while patients with preserved systolic function (PSF) are more likely to be older and female (Azevedo, 2008; Cleland et al., 2003; Fonarow, Stough, Abraham et al., 2007). In effect, this reflects the older age of onset of heart failure in women.

The heart failure study as described here was the baseline phase of a one-year follow-up study. Of 98 patients recruited, 24 (25%) had died by the one-year follow-up appointment. The mortality rate was higher than anticipated and is a source of concern. Most clinical trials report rates of approximately 10%, but this is likely a reflection of the trial inclusion and exclusion criteria and underscores the difference between patients selected for clinical trials and consecutive series of patients admitted to hospital or seen at outpatient clinics. Studies of patients hospitalised with heart failure generally report one-year mortality rates of approximately 25% (Heidenreich, Lee & Massie, 1997; McDermott, Feinglass, Lee et al., 1997). This sample was possibly ‘mid-way’ between these groups with 12% hospitalised over the course of the previous year.

Better methods of managing heart failure are needed. A systematic review of randomised trials to assess factors improving quality of life for heart failure patients (Morgan, McGee & Shelley, 2006) showed that structured management approaches achieved significant improvements. The current project sought to identify examples of such projects in Ireland and to get the views of those involved on optimal heart failure management. This is described in the following section.
7. Heart Failure Management: Innovations in Ireland

Two projects were identified as exemplars of a small but developing set of activities to promote structured chronic disease management for heart failure in Ireland. They were a programme of structured management and follow-up and a cardiac rehabilitation programme tailored for heart failure. They were based in Dublin (St. Michael’s Hospital, Dun Laoghaire, linked to St. Vincent’s University Hospital) and Wexford (Wexford General Hospital) and thus providing a flavour of differing types of programmes and regions of Ireland (urban and semi-rural). This brief study of programme participants does not aim to be nationally representative or complete but rather provides some early evidence from Irish innovations in heart failure management to inform further developments. Focus group discussions were held at both centres with relevant institutional ethics committee approval.

7.1 St. Vincent’s University Hospital/St. Michael’s Hospital: Heart Failure Exercise Clinic

The first dedicated Heart Failure Unit in Ireland was established in St. Vincent’s University Hospital in 1998. The aim of the programme is to improve the quality of life and outlook for patients with heart failure in the East Coast Area and reduce the need for repeated hospital admissions which is traditionally associated for those with heart failure condition. It seeks to empower patients to embrace self-care principles of heart failure management with strong support services for patients and family to respond to deteriorating physical and emotional well-being. An important role of the team is to communicate with other healthcare providers, incorporating primary and secondary care, relating to the changing needs of the patients as the disease progresses or improves.

The programme provides multidisciplinary heart failure care tailored to the individual patient’s needs. In addition to the two consultant cardiologists and specialist nursing staff, the multidisciplinary team also includes part-time service from a physiotherapist, dietician, psychologist and pharmacist. The 2006 Annual Report of the Heart Failure Unit estimates 4,000 patients are reviewed in the Heart Failure Unit annually.
Patients are referred to the exercise programme following heart failure education in self-care and titration of medication. Before each programme patients attend for physiotherapy assessment that lasts about an hour.

The programme runs for 8 weeks and comprises an hour of exercise twice weekly and an information session from each of the multidisciplinary team members during the 8-week course (24 sessions in total). Each programme caters for a maximum of seven patients and there are on average 13 intakes per year.

Eight participants (five men and three women) who had completed the rehabilitation programme within the previous two years attended the focus group session.

7.2 Wexford General Hospital: Heart Failure Cardiac Rehabilitation Programme

The Wexford Heart Failure Programme is a cardiac rehabilitation programme tailored to meet the needs of heart failure patients. It runs for 12 weeks and comprises an hour of exercise and an information session each week (24 sessions in total). Each programme caters for a maximum of five patients and there are generally two intakes per year. Patients are referred to the programme by hospitals following a cardiac event. The programme has been running for three years.

Seven participants (all men) who had participated in the programme within the previous year attended the focus group session.

7.3 Focus group findings

7.3.1 Experience of course

An important outcome of the programme was the increased confidence enjoyed by participants and reassurance provided following a cardiac event. It provided them with a benchmark of their health status, which they had lacked when they were discharged from hospital:

*It introduced you to the state you were in ... When I came down and got going on this course thing, you knew how far you could go and ...*
your limits. Before that I’d be with my tongue hanging out because I’d be taking bursts at things, which you shouldn’t do. I’ve settled into all that. (Centre A, R4)

Well, you get more exercise, you get to know your body better, how your heart would react and your blood and everything like that. (Centre A, R5)

Following the event for which they had been hospitalised, many of the participants were uncertain of the limits within which they could safely be physically active. The participants repeatedly referred to the monitoring of their heart rate during the exercise session, which clearly provided a safety net. This sense of security helped them to overcome the fear that engaging in exercise might have a serious negative consequence because of their heart condition:

...have a record of your blood and how your heart was and you know how far you could go. Pace yourself and you knew what you could and couldn’t do. (Centre A, R5)

It was a great reassurance for me, anyway, personally, a great confidence booster. And I’m not afraid to do things now. And I was certainly afraid before I took the course. (Centre A, R1)

I was petrified to do anything that would compromise the fairly tenuous situation that I was in, and, no, I don’t think it was bad information at the time. (Centre A, R1)

You were on the monitor, not like at home ... you weren’t being pushed, you were monitored the whole way through. (Centre A, R5)

I thought that maybe this thing will creep up behind me some day, but having done the course here, you’d be on a monitor and you saw your reactions to, you knew what you could do and what you couldn’t do and anything excess above that would definitely make a difference, it improves your heart rate and everything. That settled me down and I was quite happy then. (Centre A, R4)
The programme of exercise was a crucial kick-start to becoming functional and mobile once more:

*When I came here first I could hardly lift a cup of water, and sure I could pick two big buckets now and go where I like with them. I’d be very fit now, I couldn’t be much fitter.* (Centre A, R7)

*To live with a bad heart is, I dunno, maybe mine is a funny sort of one, but it improved a lot. And I had one of those echo tests and upped it ten percent or something. It made a difference to me, but there’s only so far I can go anyway.* (Centre A, R4)

The attention participants received and the focus on their needs boosted their morale and counteracted the sense of isolation and redundancy that often affects heart failure patients:

*It made me feel like a VIP. When you reach around 70 years of age you could write yourself off really ... I know most people write us off, but this wasn’t the case here. We felt very important.* (Centre A, R1)

*Listening to other people about other ... even cancer now, they can’t believe it, there’s so much for a heart. Follow-up after you have it. For other illnesses, you seem to be left.* (Centre A, R6)

The opportunity to share their experiences with others who have the same condition also lessened the loneliness that a diagnosis of heart failure can cause. In fact, it was apparent both from what participants said and the friendships that were clearly apparent among them that the course had been a valuable social outlet:

*And then when you see other people and start talking about it, it doesn’t seem nearly as bad.* (Centre A, R5)

*That’s one thing I would say about the group here, coming here and meeting the lads, everyone talking, express their opinion, you learn from that. There’s no point in worrying.* (Centre A, R5)
Talking to people like we are now that had the same experience is a great help because you can talk to the best doctor in the world but he’s only reading it out of a book, isn’t he? (Centre A, R2)

We’ll all meet and chat to one another, criticise one another, we’re all the time here doing devilment, have a chat, get to know people. He’d have a pain here, I’d have a pain there; we’d be all comparing our illnesses, like. (Centre A, R5)

There was some suggestion that the participants felt ill-informed about their condition prior to attending the programme. They also lacked knowledge of the tips and tricks that can help people with heart failure cope and improve their quality of life generally. According to participants, the programme addressed these gaps in knowledge effectively:

Well, when I left hospital I was given a leaflet to read and went through them in a scattered sort of a way. It was only when I came down here that they explained it in more detail, important parts of it. (Centre A, R4)

Small things there that help you along the way, very small things. I was smothering and I get an extra pillow. Small things like that made an awful difference to me ... Simple things that you wouldn’t think of on your own bat. (Centre A, R3)

One participant felt he was almost overwhelmed by the amount of information he received on the course, particularly the amount of paper material. However, no other participant expressed similar feelings.

The patient-centred nature of the programme also emerged in both settings:

You got a real feeling from the staff that they’d do anything they could for you. It was really about us and they’d go above and beyond to help you. They are great-the nurses (Centre B, R4)
Every time we sat down they were saying to us, ‘What would you like us to do? What do you think would benefit you?’, and they were amenable to any suggestion we were going to make. (Centre A, R1)

7.3.2 Access
When asked whether they had encountered any problems accessing the course, there were no problems with distance or transport in either setting. It is important to note, however, that interviews took place with those who had attended. A study such as this cannot determine if many potential participants would have problems with access to the service, although considering a partly rural and older population, it is reasonable to assume an important proportion would have difficulty if the service was extended more widely.

7.3.3 Maintenance
A number of the participants in both groups had felt somewhat cut adrift once they had completed the programme, when the routine and purpose it had provided were no longer there. Some expressed a need for continued external support in order to maintain the health-promoting behaviours that they had started on the programme. Some had failed to maintain an exercise regimen. This was put down to lack of equipment on the one hand, but the absence of the structured routine of the programme was also a factor. Once they became responsible for their own regulation, it was difficult to remain motivated. Participants who had symptoms of fatigue and breathlessness in particular, seemed less likely to maintain an exercise regimen:

When you’re finished all the things and you’re gone out, you’re on your own. (Centre A, R6)

I found I missed, the first week I slacked on everything because I had no place, I had no eleven o’clock to be up here and two o’clock to be up here. I kinda just went into a bit of a trough. (Centre A, R1)

You bet there’s no-one does anything like what we were doing when we were doing [the programme]. Because what can you do apart from a bit of walking? If it’s raining, you’re not going to go out in the rain. Some people … had an exercise bike at home, but that was it. But then
the bicycle is just like walking, isn’t it, the one thing you’re doing, whereas you have different apparatus up there to swap, like the treadmill ... It’s not the same, you wouldn’t do it on your own. (Centre A, R2)

I have a bike at home as well, and I had the lad for the two feet where you walk up and down, but I don’t get on to it ... I can’t walk either. Shortness of breath. Can’t go. (Centre A, R5)

The group was not unanimous on this point, however. Others seem to have coped better and were continuing to exercise and did not feel the need for external source of motivation:

If you’re going to exercise, you’re going to do it on your own bat ... you’re not going to be waiting to get on a treadmill here, like. (Centre A, R3)

You have to get out and do the bit of walking or whatever, if you don’t do it one day it’s always harder then to do it the next. (Centre B, R2)

One challenge to overcome in generalising lessons learned in the programme was a potential reliance on gym-type equipment for some patients. Some, as expressed above, felt reliant on the types of equipment used in the rehabilitation classes and felt they could not take exercise at home since they did not have such equipment.

7.3.4 Improvements
The participants in both locations had no criticisms of the programme per se; the only suggestion both groups made for enhancing it was to improve and expand the facilities. The programmes are run in a single room which accommodates the exercise equipment. Participants reported it gets quite cramped. It was suggested that a bigger exercise room would enable a greater number of people to benefit from each programme.

The groups were very definite that they would welcome a regular follow-up programme to maintain their focus and to reassure them that they were still on the right track. They were almost unanimous on this point. They have a need for
feedback that their self-management of the condition is appropriate and effective. Just one participant, who was ‘in top form’, didn’t feel a need for a regular ‘booster’ programme, on the basis that it would demand a time commitment and he didn’t see what extra benefit it would offer. Others outlined the value of a booster:

... if you even came back once in every three or four months - just talk or something and refresh you and bring you back down, keep you on the level again. When you’re out you’re inclined not to do things ... . (Centre A, R6)

7.3.5 GP services

Participants seemed unenthusiastic about care from their GPs, which contrasted notably with the enthusiasm they expressed in relation to the specialist care and support from Wexford General Hospital and St. Michael’s Hospital. From the discussion of the GP’s role it appeared, in their view, that the GP played a minor part in managing their heart failure condition. Participants generally seemed not to have a close relationship with their GP and to have little confidence in their GP’s ability to recognise and effectively meet their needs. One participant spoke of his GP’s unwillingness to take responsibility in managing his condition:

I got blood tests done ... with my GP, and he got the results back and he goes..........’I’m not taking responsibility for you, back to [rehabilitation facility].’ Since we finished the course, I’ve been back in [rehabilitation facility] six times. (Centre A, R4)

In relation to their general health problems (not specifically heart failure) many felt that GPs treated them in a summary manner, dispensing prescriptions without investigating the problem:

You go with a pain or an ache to them and they’ve no test much for it, ah sure, give you an aspirin, give you Difene, give you something else for a week or a fortnight and come back. That’s my main objection; there should be more serious looking into, like. (Centre A, R5)

I can tell you my GP will give me Augmentin, Plavix, four different antibiotics if I have a cold and I could do the job myself like. I can say, will I give you Augmentin today, or will I give you Plavix? And I have
never got anything different except when my platelets went very low, they gave me some steroids. (Centre A, R1)

The GP was not seen as the first point of contact for these patients if a medical need arose. An appointment might not be available when it was needed. Even if it was, many participants were not confident that the GP could deal adequately with the situation. Instead they believed that GPs would simply send patients to hospital as a matter of course. If they needed advice, participants were much more likely to contact the hospital that was treating them or the cardiac unit in Wexford Hospital or St. Michael’s Hospital:

And about your GP, sometimes when we ring our GP, we might get an appointment a fortnight from today. You’d nearly have to get an ambulance to deliver you to the door. (Centre A, R1)

But if you have a problem at home, something went wrong with you, like what happened to me once, the last place you’d be going to would be to your GP, you’d go straight to the hospital or to the heart unit here. (Centre A, R6)

The participants were unenthusiastic about a proposal that GPs provide heart failure rehabilitation programmes. They felt that GP surgeries would not have the space nor the facilities to accommodate a programme. They also felt more secure doing the programme within a hospital setting:

They’re only moving the problem from there to there ... What’s the point in taking the funding from here and putting it there? ... I’d sooner go here than to the GP. (Centre A, R6)

They know me here, they know what I’ve been through and what I need. He (the GP) doesn’t know the half of it. (Centre B, R7)

We also know if we go down in a heap [collapse], we couldn’t be in a better place. (Centre A, R1)
7.3.6 Quality of care
During the discussion, several participants expressed frustration at the lack of continuity in their care - for example, the doctor to which they were referred not being available when they attended for appointments, or their regular doctor being replaced by a locum who changed their medication, which did not work. The heart failure programme contrasted with this experience of medical treatment. Three/four nurses ran the programme and were there consistently when participants attended. This opportunity to build a relationship with the professionals caring for them was undoubtedly an important aspect of the programme for participants. From the interactions and comments made on the day, it was clear that the patients in both groups and nursing staff with whom they worked closely shared a very good rapport.

7.3.7 Labelling of condition as ‘heart failure’
One participant expressed his aversion to the term ‘heart failure’. The term itself had a discouraging effect on him when he was first diagnosed, and he wished for an alternative. Two other participants disagreed, however, and believed it had made no difference to their response to their diagnosis:

It’s defeatist, we’re failed before we start. I know it would be long-winded and all, but impaired heart function or something like that but the nurse came to me and I in the bed and I wasn’t well at all ... and she gave me these leaflets, Living with Heart Failure and I said, ‘That’s some motivation, living with heart failure.’ (Centre A, R1)

You still have the condition, you can call it what you like, you still have the condition. To me it doesn’t matter. Now I’m not saying that I’m right. If you lose a leg, you lose a leg, you can’t do anything about it. (Centre A, R3)

When I came to, it never bothered me what was wrong, I was still alive. I was like that for three weeks. It didn’t matter where I went or what they done, I was happy to be alive and it got me over the shock of it and all. (Centre A, R6)
7.3.8 Medication

In both hospitals a pharmacist is available as part of the multidisciplinary team to give patients advice and answer any questions that may arise. The importance of understanding their medication, why it was prescribed and any side effects that might arise, are highlighted.

When asked about their medication, no one expressed difficulties in maintaining a medication regimen. Most seemed to have accepted that their condition demanded a complex medication regimen though some expressed exasperation with constant changes to their regimens, slowness of new medications to take effect and side effects:

They never explain to you – ‘take him off that and put him on this’. There are so many side effects, you’d nearly say will I take them at all. (R5, Centre A)

Participants highlighted the need to be organised and to maintain a routine with regard to taking their medication:

You just get used to it, you’ve a certain number of tablets and you just have to take them. That’s the way it goes. I find the containers great (pill containers with individual compartments) so you know what you have to take every day and when you’ve already taken it. (Centre B, R5)

In summary, one participant summarised many of the points raised in focus groups about the value of the programme, as follows:

It would be a terrible shame if this kind of activity was one of the casualties [of HSE cutbacks] because.......I’m a new man.....I think this is a proactive programme and I know some people might say them are old has-beens. I don’t feel like an old has-been. I actually have XX of a family and XX grandchildren and we’re kind of full-time babysitting now but its great we’re able to do that. (Centre A, R1)
8. Conclusions

Patient findings show relatively high satisfaction with aspects of quality of care. The opportunity to take part in a heart failure management programme, learning lifestyle skills as well as a greater understanding of heart failure as a condition and an opportunity to spend time with professionals and others with the same condition was clearly a valued service for heart failure patients. From the larger patient study, it was obvious that many patients do not undertake the recommended self-care activities. There was a high level of hospital service use. Programmes which could address this, by enabling patients to become expert at managing their condition and by developing a shared care approach across primary and secondary care, would improve the overall quality and efficiency of care. Models of shared care between hospital and primary care need to be established so that patients can be managed in primary care where appropriate. This will require investment in liaison of personnel between hospital and community to establish how rehabilitation and maintenance programmes can be delivered for the most effective and efficient management of heart failure. A hospital-only model is not likely to be sustainable, particularly if there are to be means to support patients with less frequent but regular opportunities to refresh and seek to maintain skills learned in a first intensive course. A community role needs to be established to make best use of the respective skills and resources of the specialist centre and the primary care team. The ‘prevention centre’ concept – a community one-stop resource supporting patients with chronic disease to adopt and maintain healthy living with group sessions involving physical activity, diet, smoking cessation – could provide the support for maintenance that heart failure patients need. Development of shared care needs to include patient appreciation of the merits of such care.

While patients in the larger study reported high levels of satisfaction with their general care from GPs, patients in the rehabilitation groups were less confident about GP expertise when asked more directly about managing issues concerning their heart failure care. The differences are likely to be because of the extent of tailored care provided to the rehabilitation attendees. A challenge in the future will be to develop rehabilitation or chronic disease management services for heart failure that do not undermine the role of the GP in ongoing management of patients for their heart failure and other conditions. Guidance regarding the interface of primary and secondary care is needed to manage the development of
heart failure services. This should occur within the cardiovascular network model envisaged in the upcoming Cardiovascular Health Policy. In this model, heart failure services will be managed within geographic regions with closer links between the primary and secondary care sectors, including outreach from hospital specialists and more rapid access to specialist evaluation by GPs in order to minimise unavoidable admissions.

More generally, regarding programme development and needs, there is a dearth of information on the numbers of patients requiring management of heart failure and on the numbers currently included in rehabilitation programmes in Ireland. A National Heart Health Action Plan for Heart Failure needs such information as a benchmark for service development and later evaluation. An audit of patient numbers, patients currently receiving rehabilitation and the rehabilitation capacity of cardiac rehabilitation programmes to absorb these patients should be undertaken. As a starting point, those newly identified as heart failure patients in hospital settings in 2010 could be quantified. Then the rehabilitation opportunities of these patients, and the resources needed to provide rehabilitation could be assessed. Many of the resources needed may be add-on resources, particularly in the form of staffing, to existing cardiac rehabilitation programmes. This benchmark would provide both the opportunity to plan and to evaluate progress in the National Action Plan. It is expected it would also fit with the aspirations of the upcoming Cardiovascular Health Policy (Changing Cardiovascular Health) which will be launched in winter 2009 and with a new National Rehabilitation Strategy which is at consultation phase in 2009. What is clear from figures on hospital use for heart failure over the past decade, as outlined in the introduction, is that a new approach is needed to manage heart failure that is preventive, supports educated self-care, builds alliances between primary care and hospital professionals, and minimises hospital admissions – all with the goal of doing better for the patient.

A number of implications for service development can be summarised from this engagement with Irish heart failure patients – the large-scale structured interview study of hospital outpatients followed over one year and the smaller focus groups of patients who have completed rehabilitation programmes tailored for heart failure.
IMPLICATIONS FOR SERVICE DEVELOPMENT

1. **Structured management:** With increasing numbers of heart failure patients, structured management programmes are needed to maximise self-care and promote effective coordinated use of primary and secondary care services. This will slow disease progression and minimise the numbers of emergency episodes of care needed in this chronic condition.

2. **Early detection and education:** Structured management begins with early detection of heart failure and education about heart failure. This needs to include dimensions of self-care from lifestyle change to medication adherence to appropriate healthcare engagement.

3. **Heart failure programmes:** Patient education is best delivered in a programme of care addressing both knowledge and skills development. This includes addressing physical activity, dietary, smoking and other lifestyle issues. It also includes learning appropriate responses to signs and symptoms of heart failure or its exacerbations – in order to minimise clinical damage and/or emergency use of healthcare when with an earlier response it could be averted. Expertise in programme development is available through cardiac rehabilitation programmes in many centres and through existing exemplar projects that work specifically with heart failure groups in Ireland. Patients must be supported to develop physical activity routines that generalise beyond the equipment and structured routine of the formal rehabilitation setting.

4. **Shared care:** Models of shared care between hospital and primary care need to be established so that patients can be managed in primary care where appropriate. This will require investment in liaison of personnel between hospital and community to establish how rehabilitation and maintenance programmes can be delivered for the most effective and efficient management of heart failure. A hospital-only model is not likely to be sustainable. A community role needs to be established to make best use of the respective skills and resources of the specialist centre and the primary care team. Development of shared care needs to foster patient appreciation of the merits of such care.
5. **Audit:** Regarding programme development and needs, there is a dearth of information on the numbers of patients requiring management of heart failure and on the numbers currently included in rehabilitation programmes in Ireland. A National Heart Health Action Plan for Heart Failure needs such information as a benchmark for service development and later evaluation. An audit of patient numbers (those known in the hospital system in the first instance), patients currently receiving rehabilitation and the rehabilitation capacity of cardiac rehabilitation programmes to absorb additional patients should be undertaken. As a starting point, those newly identified as heart failure patients in hospital settings in 2010 could be quantified. Then the rehabilitation opportunities of these patients and the resources needed to provide rehabilitation could be assessed. This benchmark would provide both the opportunity to plan and to evaluate progress in the National Action Plan.

In conclusion, the information provided here provides some perspectives from patients living with heart failure in Ireland today. There is much that they are satisfied with about current service delivery. Those who were managed through a multidisciplinary chronic disease management programme tailored for heart failure were enthusiastic about its contribution to their quality of care, their quality of life and their self-care and lifestyle management. The challenge is to make such opportunities for education and support with heart failure the norm for the much wider group of heart failure patients who exist now and will grow in numbers into the future.
References


