Review of Specialist Heart Failure Nurse Services

Scotland 2013

Chest Heart & Stroke Scotland

The SHFNF is an independent organisation, supported by Chest Heart & Stroke Scotland and BHF Scotland

British Heart Foundation SCOTLAND

The Scottish Heart Failure Nurse Forum

The Scottish Heart Failure Nurse Forum (SHFNF) was launched as an independent organisation in 2005 for the benefit of registered nurses working primarily in the specialist management of patients with heart failure in Scotland. SHFNF membership is representative of every area of Scotland and currently hosts two educational meetings per annum. The SHFNF also holds membership of the Heart Disease & Stroke Cross Party Group (at the Scottish Parliament) and the Scottish Government's National Advisory Committee for Heart Disease (NACHD).

The first SHFNF Review was published in 2008 to highlight the role and distribution of Specialist Heart Failure Nurses across Scotland. This document was shared with a number of organisations, including Managed Clinical Networks (MCN) and the Scottish Government Health Directorate.

"A review of specialist heart failure services in Scotland, published in the autumn of 2008 by Chest Heart & Stroke Scotland and the British Heart Foundation on behalf of the Scottish Heart Failure Nurse Forum, highlighted areas in need of resources and investment to meet the rising number of those requiring specialist support"
(Better Heart Disease & Stroke Care Action Plan 2009).

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Foreword

Foreword by Suzanne Bell, Chair of Scottish Heart Failure Nurse Forum, on behalf of members.

This Review welcomes the wide range of contributions received as a result of the SHFNF Committee consultation with Specialist Heart Failure Nurse services across Scotland. We focus on the role of the specialist nurse, but remain mindful of the extensive collaboration with the multi-disciplinary teams and the invaluable support provided by clinicians in providing safe and effective care to those living with heart failure and their families.

Our initial review (completed in 2008), was widely circulated and well received by health professional services, Managed Clinical Networks, NHS Boards, the Scottish Government and Members of the Scottish Parliament. The first review of its kind, it sought to raise awareness of this group of highly qualified and experienced specialist professionals. The 2008 Review demonstrated the significant impact achieved through raising standards of care and support for those living with heart failure and raised awareness of the need for Boards to commit to specialist posts, instigated though British Heart Foundation funding.

The 2013 Review aims to highlight many of the current challenges and issues affecting these services. This Review is underpinned by recent guidelines and current published statistics. The willingness of our membership to collate and share a wealth of information for this Review, reflects their belief in the value of their roles and their ambition that Scotland leads the way with comprehensive, well resourced and sustainable services for heart failure.

Since formalisation in 2005, the SHFNF has steadily increased its influence across NHS Scotland with inclusion in the many agencies concerned with developing health policy. In striving to share the views of our membership at national level, we are also very grateful for the support of the Scottish Government and particularly the National Advisory Committee for Heart Disease in taking action on the key issues that we have raised. We also commend the decision to fund the HEART-E on-line training programme being developed by Chest Heart & Stroke Scotland, which includes a module on heart failure education.

Heart failure is a life-limiting condition and people can live with disabling and isolating symptoms for many years. Healthcare Improvement Scotland's 2011 review of NHS QIS Standards, indicated that patients with heart failure are not always receiving appropriate care. Across all of Europe the number of people living with heart failure is increasing (European Society of Cardiology 2011), yet in Scotland, the number of Specialist Heart Failure Nurses is falling. Input from these professionals with the skills, knowledge and expertise to manage the complexities of the condition has demonstrated a decrease in hospitalisation with reported evidence suggesting that heart failure nurses can save an estimated £1826 per patient realised through a 35% reduction in hospital admissions (University of York 2008).

This 2013 Review is able to demonstrate comparable outcomes in cost effectiveness across the clinical practice of our Specialist Heart Failure Nurse members. **Specialist Heart Failure Nurse services across Scotland reduce unplanned hospital admissions and reduce length of hospital stay.**

Despite this...

...and (with the exception of only 4 NHS Board areas), NHS Boards are failing to meet even the minimum ratio of Specialist Heart Failure Nurse numbers to population level (SIGN 2007);

...our Review reports that the overall number of Specialist Heart Failure Nurses has now fallen to 47.17 Whole Time Equivalent (WTE) posts, (compared to 51 WTE in the SHFNF Review in 2008);

... only 3.1% of people living with heart failure are included in the provision of cardiac rehabilitation. In 2010 Healthcare Improvement Scotland recommended that NHS Boards should be extending menu-based cardiac rehabilitation services across a broad range of patient groups, focusing on those that have previously received cardiac rehabilitation services.

The 3rd Report of the Scottish Parliament Public Audit Committee (Session 4) 2012, requests **'clarification from the Scottish Government on the future plans for heart failure nurses across Scotland'**, a statement that on behalf of our membership, we would endorse and also request clarity.

To support this and within the context of the continuing prioritisation of the needs of those living with heart failure across all service provision, the vision of the SHFNF membership is for a national approach to the planning, adequate resourcing and further development of Specialist Heart Failure Nurse services to enable them meet to the ever increasing challenge of the one cardiac condition with which morbidity levels continue to rise.

Suzanne Bell
Scottish Heart Failure Nurse Forum Chair

The information contained within this document is representative of Specialist Heart Failure Nurse services in Scotland as of September 2012.

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Aims

The aims of the 2013 SHFNF Review are to:

- **Set out the principles of quality care for people with heart failure**
    - Highlight the complexity of people living with long-term conditions
    - The specialist skills required by nurses to deliver safe, effective care
    - The role of the Specialist Heart Failure Nurse in promoting self-management
- **Demonstrate the cost-effectiveness of the Specialist Heart Failure Nurse model**
- **Highlight the factors across Scotland, which impact on the provision and delivery of Specialist Heart Failure Nurse services.**

This document complements the current guidelines for the management of heart failure and key government policy on the management of long term conditions.

> *"Nothing is ever a problem, all information and advice we need is explained in a friendly and compassionate manner and the team are always available whenever we have a problem or just want to talk. They show an interest in our family life and know each and everyone of us by name. This in itself is reassuring and shows that we are not just another family but that this team really do care"*
>
> *(Family member – NHS Forth Valley)*

Heart Failure

Heart failure is a complex clinical syndrome that can result from any structural or functional cardiac or non-cardiac disorder that impairs the ability of the heart to respond to physiological demands for increased cardiac output. The terms used to describe different types of heart failure can be confusing (European Society of Cardiology 2012).

Left Ventricular Systolic Dysfunction (LVSD):
impairment and abnormality within the main pumping chamber of the heart (left ventricle).

Heart Failure with Preserved Ejection Fraction (HF-PEF):
impairment of the pumping of the heart, with no obvious abnormality of the main pumping chamber (left ventricle).

The focus of this report is on LVSD as evidence-based treatment is available and pathways of care for this type of heart failure are well defined. People living with heart failure due to LVSD also form the majority of the Specialist Heart Failure Nurses' caseload.

Complexity of heart failure

The predominant causes of heart failure are coronary artery disease, hypertension, valve disease and cardiomyopathies. Common symptoms include increasing breathlessness and fatigue as well as fluid retention (European Society of Cardiology 2012). It is a progressive condition and in an ageing population is often present in conjunction with multiple co-morbidities, which bring a multitude of additional symptoms.

"Improved survival rates from acute myocardial infarction and the demographics of an ageing population mean that heart failure is becoming an increasingly prevalent condition, often associated with the presence of other diseases."

(Better Heart Disease & Stroke Care Action Plan 2009)

In order to determine the best course of therapy, the stage of heart failure is assessed according to the New York Heart Association (NYHA) functional classification system (see Appendix One). This system relates symptoms to everyday activities and the patient's quality of life.

The management of heart failure involves complex medical therapies and careful monitoring of medications; in addition, there are psychosocial and behavioural factors for both patients with heart failure and their caregivers (McAlister et al 2004).

Prevalence of heart failure

Across Europe there has been a general decline in mortality from cardiac conditions, with death rates in Scotland falling by around 40% since 2000 (General Registrar for Scotland 2011). The prevalence of heart failure however is the one cardiac condition which continues to rise. This is due to changing demographics (e.g. ageing population) and improved survival from cardiac conditions in earlier life (European Society of Cardiology 2011a). Additionally people are living longer with heart failure due to improved management of existing cardiac conditions and specialist heart failure care including Specialist Heart Failure Nurses.

The Quality Outcomes Framework (QOF) 2011 heart failure registers estimated the prevalence of heart failure at 0.8-0.9% in the general population (ISD 2011). The General Registrar Office (GRO) for Scotland's 2011 figures estimate the population at 5,254,800 (www.gro-scotland.gov.uk). Therefore based on prevalence estimates within QOF, 42,038 – 47,293 people were living with diagnosed heart failure in 2011; the QOF registers for 2010 contain 42,118

patients (ISD 2012). These figures are based on people diagnosed with only one type of heart failure – LVSD (see introduction for information on the types of heart failure) and currently the only type for which we have accurate data within Scotland.

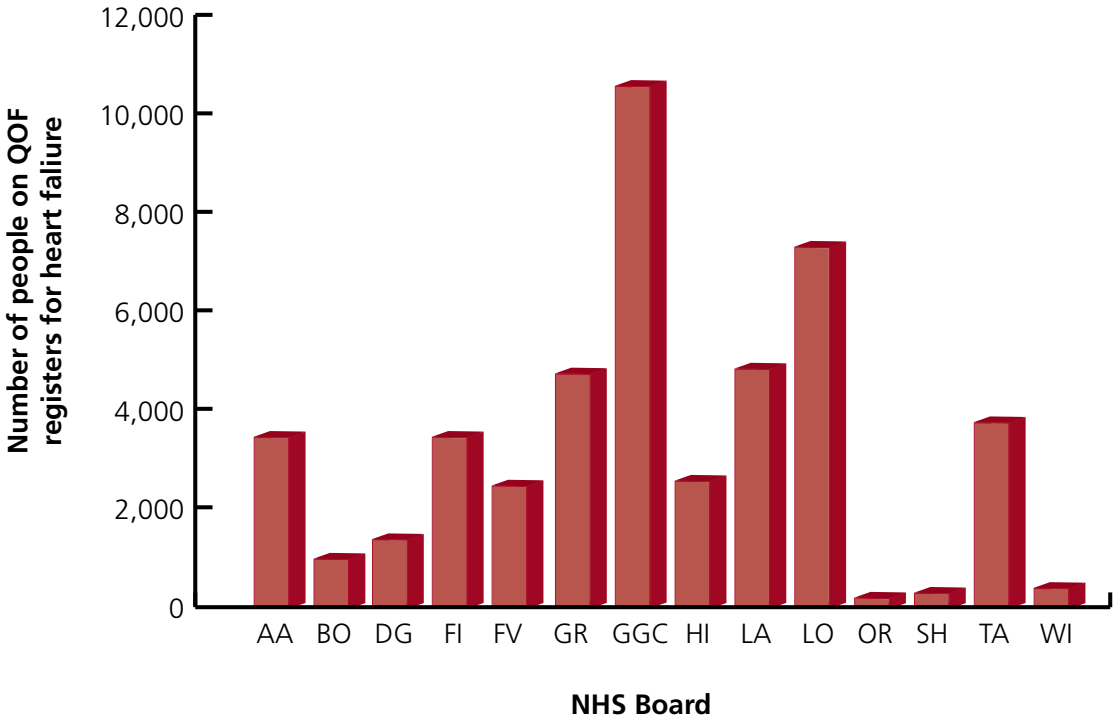


Fig. 1: Quality Outcomes Framework (QOF) 2011 estimates on prevalence of heart failure

It is widely accepted that QOF figures underestimate the true prevalence of heart failure as an unknown proportion of those living with the condition are undiagnosed (France et al 2010) Information Statistics Division Scotland (ISD) estimates have placed the total number of those living with the condition at a much higher level of 100,000 in Scotland; this is in line with UK estimates.

Within the UK population, British Heart Foundation Heartstats (BHF 2010) estimated the prevalence of heart failure to be 3% of those over 45 years, 7% of those over 75 years and 15% of those over 85 years of age.

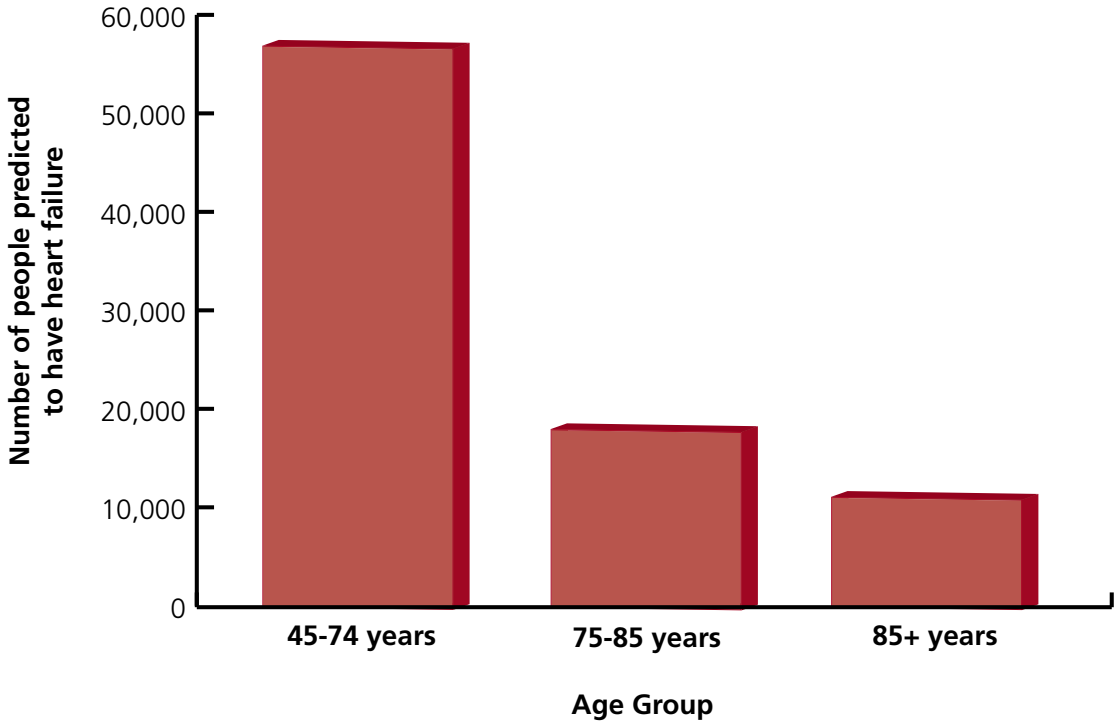


Fig. 2: Estimated prevalence of heart failure in the general population (BHF 2010)

These 'heartstats' prevalence estimates applied to the current age related statistics of the Scottish population (General Register Office for Scotland 2011) suggest that almost 94,000 people are living with heart failure in the community today.

Management of heart failure

The management of heart failure is multifaceted and requires significant efforts by patients and healthcare providers alike to optimally manage the condition (McKee 2009) within multi-professional systems of care (European Society of Cardiology 2011). The Scottish National Heart Failure Audit showed that the majority of patients with heart failure in the acute setting are managed by a diverse group of clinicians in non-cardiac specialist wards; 70% of in-patients were managed by non-cardiologists (NHS National Waiting Times Centre 2011).

Optimal treatment for heart failure due to LVSD includes a combination of complex pharmacological therapies, behavioural modification and clinical interventions (Scottish Intercollegiate Guidelines Network 2007a). The management of people living with heart failure requires ongoing monitoring and frequent adjustments to treatment based on symptoms, in line with national and international guidelines. The management of people with HF-PEF is challenging for the multi-disciplinary team as there are currently no evidence-based guidelines available.

'Better Health, Better Care Action Plan' (Scottish Government 2008a) suggested that in order to provide effective health care, the challenge is to provide ongoing continuous care with an emphasis on anticipatory care rather than reactive care. It suggested that specialist holistic care will provide real benefits to those with long term conditions such as heart failure. A high level of specialist care in partnership with the multi-disciplinary team has been proven to reduce readmission rates from heart failure (Blue et al 2001; Rich et al 1995). Specialist Heart Failure Nurses are at the forefront of delivering this continuity of care and anticipatory approach by delivering specialist follow up immediately after discharge.

Patients are reviewed by specialist nurses in a variety of settings: hospital wards, outpatient clinics, satellite clinics and in their homes. Most Specialist Heart Failure Nurse services also offer telephone support for patients, carers and General Practitioners (GP) to access advice regarding symptom management. The model of service delivery varies throughout the country depending on geographical location and available resources. Investigations and treatment are based on current national and European clinical guidelines: Scottish Intercollegiate Guidelines Network (SIGN), National Institute of Clinical Excellence (NICE) and the European Society of Cardiology (ESC).

Specialist Heart Failure Nurses have a fundamental role in managing and monitoring these treatments and facilitating self-management strategies.

'Self-management includes a whole spectrum of mechanisms to support people to learn about their condition, acknowledge the impact it has on their life, make changes/adapt and identify areas where they require support' (LTCAS 2008).

Organised systems of specialist heart failure care delivery have been shown to improve outcomes and quality of life, as well as survival in heart failure (Jaarsma 2005).

The Specialist Heart Failure Nurse

Specialist skills required to deliver safe, effective care

A 'specialist nurse' is regarded as someone with in-depth knowledge and skills in the specialty (NES 2008). Specialist Heart Failure Nurses possess high levels of skill, many have advanced clinical assessment qualifications and are able to prescribe and many are educated to Masters level.

In September 2012, members of the SHFNF were surveyed to ascertain their educational qualifications:

- A health related undergraduate degree is held by 70% of members;
- A health related Masters degree is held by 33% of members;
- All respondents had completed cardiac/heart failure specific degree level modules, with 94% successfully completing the Glasgow Caledonian University core Heart Failure module.

Additional educational achievements include:

- The attainment of non-medical prescribing qualifications by 42% of members;
- The attainment of the Glasgow Caledonian University specialist Palliative Care in Heart Failure degree level module by 39% of members.

Members have also undertaken advanced study in a number of other relevant areas including; counselling skills, clinical assessment, pharmacology, motivational interviewing and advanced communication, along with 42% of members noting that they had undertaken additional study outwith the categories of the survey.

When patients have other long-term conditions, which is often the case as heart failure rarely occurs in isolation, this diverse and comprehensive skill set positively contributes to the support and management of multiple symptoms and liaison with other health professionals.

Cost-effectiveness of the Specialist Heart Failure Nurse model

The first study to examine the potential economic benefit of a Specialist Heart Failure Nurse service was conducted by Stewart et al in 2002. The researchers concluded that such a service not only improved quality of life and reduced re-admissions, but could *'reduce costs and improve the efficiency of the healthcare system in doing so'*.

The Scottish National Tarriff 2011-12 (ISD 2010) places a cost of £2,798 per non-elective admission for heart failure, rising to £4,551 if the patient requires admission to a Coronary Care Unit. For comparison, a non-elective general cardiac admission is costed at £986.

Although there has been a 28% reduction in the number of patients with heart failure admitted from 5,090 in 2001 to 3,679 in 2010 (throughout the years that Specialist Heart Failure Nurse services have been operational in Scotland), the median length of stay for patients with heart failure remains the highest of all cardiac conditions at eight days. Patients with heart failure account for 25% of the bed days among all cardiac conditions (Audit Scotland 2012).

'The value of specialist nurse practitioners in reducing subsequent hospitalisations for patients admitted to hospital with decompensated heart failure has been shown in a number of studies in mainland Europe, the USA, Australia and Scotland.' (European Society of Cardiology 2011a)

One of the longest established Specialist Heart Failure Nurse services (Dumfries & Galloway) has analysed the changes in emergency hospital admissions, bed days and average length of stay per patient over the 10 years since their service commenced.

Among those with LVSD in the service caseload, since 2002 they have shown:

- 44% reduction in hospital stays (D&G hospitals)
- 28% reduction in bed days
- 20% reduction in average length of stays per person (measured in days).

One of the newest Specialist Heart Failure Nurse services on the Western Isles has demonstrated a reduction in bed days over 5 years, since the service was launched. In September 2007, there were 633 bed days due to worsening heart failure but by 2011 this had reduced to 250 bed days, a reduction of 60.5%. It is acknowledged that there are many factors, which could impact on a reduction in bed days, however within NHS Western Isles there is no Consultant Cardiologist and no specialist admission unit, which would indicate a positive correlation with the reduction of bed days and the introduction of the Specialist Heart Failure Nurse service.

A clinical audit in NHS Tayside (2011-2012) found that within the service caseload only 8.3% of patients experienced a deterioration leading to an unplanned admission, compared with a readmission rate of 27.3% for those patients being managed out with the service.

The BHF Evaluation of Heart Failure Nurse Services in England (University of York 2008) found that in the area studied, only 18% of patients with heart failure under the care of a Specialist Heart Failure Nurse were readmitted to hospital, compared to 97% of those without specialist support, with an impressive 35% reduction in all-cause admissions. Patients under the care of the 76 Specialist Heart Failure Nurses audited also had shorter lengths of stay (8.6 nights v 11.6 nights). The report concluded that this could equate to a saving of approximately £1,826 per patient, a saving which also incorporates the costs of the specialist post.

The evidence and the actual reported experience of the Specialist Heart Failure Nurse services in Scotland would suggest that the presence of such a service can prevent unplanned readmissions, reduce length of hospital stays and ultimately create a cost saving for the NHS.

Cardiac rehabilitation for heart failure

The Scottish Campaign for Cardiac Rehabilitation was jointly launched by BHF Scotland and Chest Heart & Stroke Scotland in March 2008. Figures demonstrated that less than 1% of all patients with heart failure in Scotland were receiving Cardiac Rehabilitation. The campaign was endorsed within the Better Heart Disease & Stroke Care Action Plan 2009, with specific reference to the needs of patients with heart failure: "The specific rehabilitation needs of those with heart failure also need to be borne in mind."

One of the campaign key objectives was to instigate a national audit of cardiac rehabilitation in Scotland and this was carried out by ISD with the support of Healthcare Improvement Scotland (HIS) between 1st April 2010 - 31st March 2011.

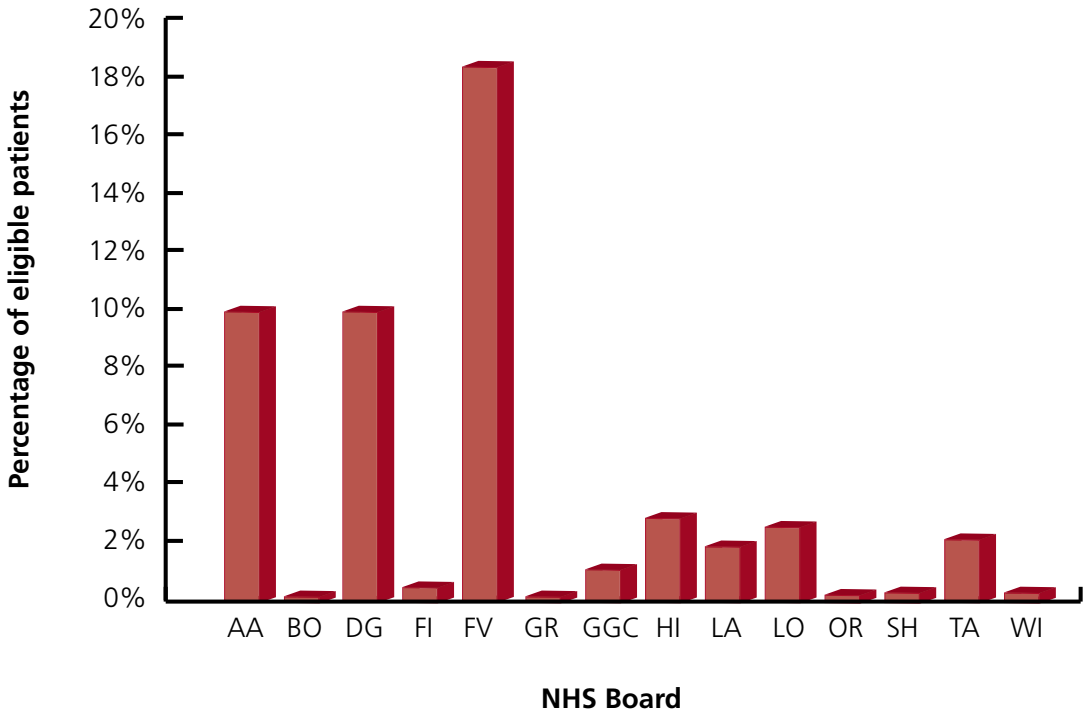


Fig. 3: Percentage of those living with heart failure referred for cardiac rehabilitation, by NHS Board 2010-2011

The ISD 2012 data proposed an eligibility total of 4,599 patients with heart failure, which is based on hospital admission with an initiating event of heart failure and adjusted for mortality. Disappointingly, since 2008 there has been little discernible change in referral and assessment rates for cardiac rehabilitation in heart failure. The latest audit figures reveal that only 3.1% of eligible patients with heart failure were referred, with only 2% of those eligible completing rehabilitation. Three Boards have notably higher figures with 10% of eligible patients with heart failure referred for rehabilitation in both Ayrshire & Arran and Dumfries & Galloway and 19% referred in Forth Valley (ISD 2012).

In 2010, NHS QIS Standard Ten Cardiac Rehabilitation set the standard for cardiac rehabilitation in heart failure (see Appendix Two), reinforced by Healthcare Improvement Scotland's recommendation that NHS Boards should be extending menu-based cardiac rehabilitation services across a broad range of patient groups focusing on those that have not previously received cardiac rehabilitation services, including people with heart failure (Healthcare Improvement Scotland 2011).

Members of the SHFNF were questioned about availability of cardiac rehabilitation for their patients. Where it was reported as being available, we then asked the services to confirm the number of patients who had accessed cardiac rehabilitation in the previous year and these results are listed on the right-hand side of the table (Fig. 4). There is no access to rehabilitation for patients with heart failure in 3 Boards and only limited access in another 2 Boards. Healthcare Improvement Scotland used four categories in their 2011 assessment: 'developing'(D), 'implementing' (I), 'monitoring' (M) and 'reviewing' (R), which relate to compliance of each NHS Board with the standard, with 'reviewing' indicating compliance (for definitions see Appendix Two).

NHS Board	HIS Assessment 2011 (Standard Ten)	CR available (SHFNF report)	Number accessing CR	SHFNF Reports – actual compliance
AA	M	Yes	80	M
BO	M	No	0	D
DG	M	Yes	53	M
FI	M	Limited	Unknown	I
FV	M	Yes	50	M
GR	D	No	0	D
GGC	R	No	0	D
HI	D	Limited	Unknown	D
LA	I	Limited	3	I
LO	M	Yes	Unknown	M
OR	I	Yes	Unknown	I
SH	I	Yes	20	I
TA	I	Yes	25	I
WI	I	Yes	20	I

Fig. 4: Reported compliance with NHS QIS Standard 10 (2010) relating to cardiac rehabilitation in relation to meeting the needs of the patient with heart failure.

There appear to be inconsistencies between HIS 2011 assessment and reported access to cardiac rehabilitation from SHFNF members. For example, NHS Greater Glasgow & Clyde reported their compliance with Standard 10 as being at 'reviewing' stage but currently offer no service to their population with heart failure. Borders and Fife NHS Boards both reported 'monitoring' with no service in place for patients with heart failure. The right-hand column illustrates the SHFNF findings in relation to compliance with Standard 10 (NHS QIS 2010), with specific reference to meeting the rehabilitation needs of the patient with heart failure.

There is a growing body of evidence to support the inclusion of patients with heart failure in cardiac rehabilitation programmes and a recent Scottish study found significant improvement in fitness and walking ability within a hospital based programme (Cowie et al 2011). A study from South Australia examined the cost saving due to a decrease in readmissions for those participating in cardiac rehabilitation programme over 3 months. The study concluded that for every $1 (Australian dollar) spent on providing cardiac rehabilitation, the hospital saved $11.50 on admissions prevented (Barnard et al 2012).

Supportive and palliative care

The palliative care needs of people living with heart failure are widely acknowledged within policy documents. The framework for a palliative approach in heart failure (Scottish Partnership for Palliative Care 2008), provides recommendations for health and social care professionals in recognising and supporting patients at the latter stages of the condition and the Living and Dying Well national action plan reinforces the need to offer a palliative approach to all patients with end of life care needs (Scottish Government 2008b).

Quality of life in those living with heart failure is often worse than any other long-term condition and the condition carries a worse prognosis than many cancers (Rogers et al 2000; Juenger et al 2002). Within 5 years of diagnosis, up to 50% of patients with heart failure will be dead. Mortality rates among newly diagnosed patients are 6% in the first month, 11% in the first 3 months and 14% in the first 6 months (Cowie et al 2000).

The aim of supportive and palliative care is to optimise planning to avoid futile treatments, investigations and distress for patients and their families at the end of life (National Heart Forum of Australia 2010).

Patients with heart failure who remain symptomatic despite optimal treatment have physical, psychological, social and spiritual needs that may benefit from supportive and palliative care leading to improved quality of life (NHS QIS 2010).

The Specialist Heart Failure Nurse is in a unique position to identify patients requiring a palliative care approach. Continuity of care is a pre-requisite to being able to detect subtle changes in the condition, which can often be unpredictable, and may indicate a decline. By identifying these patients early, the specialist nurse plays a pivotal role in coordinating and implementing advanced care planning with the patient, carer and appropriate members of the multi-disciplinary team.

'A joined up, consistent approach improves quality of life for the patient and family/carer' (NHS QIS 2010).

The NHS QIS (2010) audit highlighted that despite the requirement for regular needs assessments to ensure that appropriate supportive care was in place, only 2% of patients on GP Palliative Care registers had heart failure. Both the high mortality and increasing prevalence of heart failure would indicate that this is a surprisingly low number and raises concerns as to the availability of specialist support for the majority of those living with the condition.

Provision of Specialist Heart Failure Nurse Services

Between the first SHFNF Review in 2008 and this 2012 edition, the national total of Specialist Heart Failure Nurses dropped by 7% (50.7 WTE to 47.17 WTE posts) despite members reporting increasing caseloads, as well as an increase in the complexity of individual cases.

In 2008, 15 WTE posts were funded by the BHF and it is encouraging to note, that in 2012, all 47.17 WTE Specialist Heart Failure Nurse posts in Scotland, are funded by the NHS. Although this change to substantive funding is a positive sign, the overall drop in WTE posts would indicate that NHS Boards are not supporting the ongoing development of services.

Distribution of Specialist Heart Failure Nurses in Scotland

In 2012, with the exception of NHS Orkney, all NHS Boards have an operational Specialist Heart Failure Nurse service.

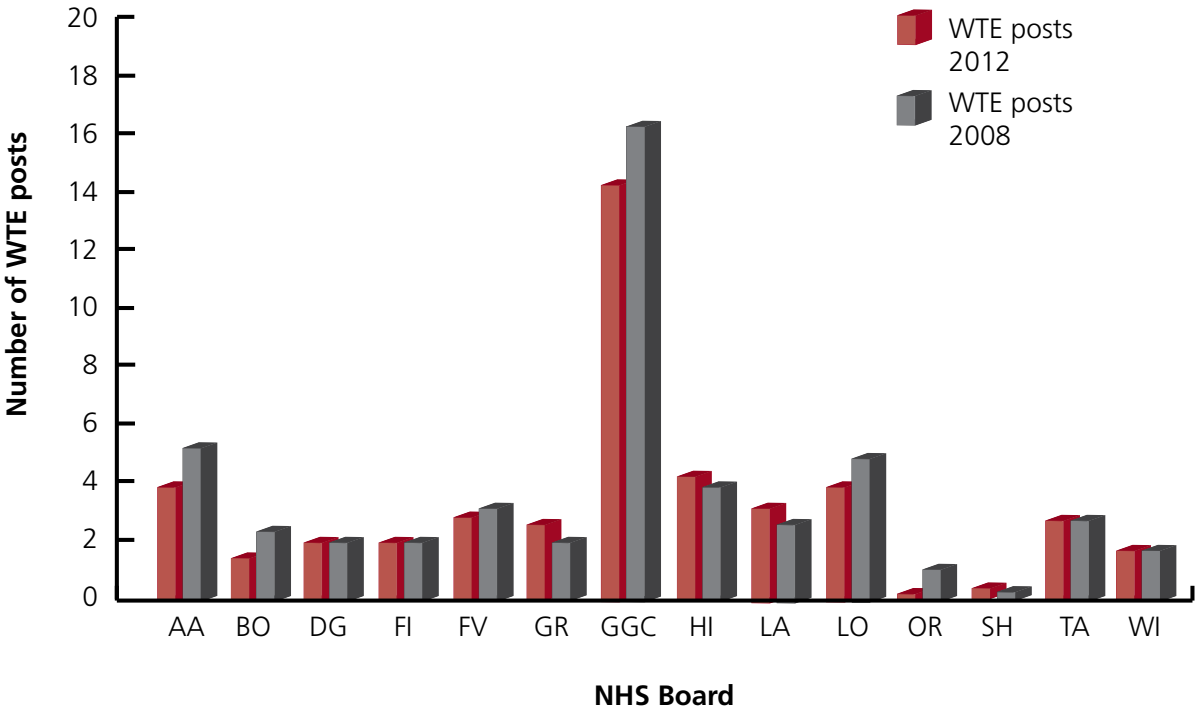


Fig. 5: Whole Time Equivalent (WTE) Specialist Heart Failure Nurse posts in 2012 and 2008, by NHS Board

However, the level of WTE posts dropped in 6 NHS Boards between 2008 and 2012: Ayrshire & Arran, Borders, Forth Valley, Greater Glasgow & Clyde, Lothian and Orkney (in Orkney there is no service currently provided). In 4 areas and despite increasing demand, there was no change from 2008. Four areas had very small rises in WTE posts, with the largest increase in Grampian, an increase from 2 WTE to 2.65 WTE. Grampian had a break in service between 2007 and 2009 and therefore this rise primarily reflects the re-establishment of service provision.

In order to provide comprehensive follow-up on discharge, up to 50 nurses and 10.5 administrators were estimated to be required to allow symptomatic patients to receive nurse-led home-based services (SIGN 2007a). A service with 50 nurses would provide one Specialist Heart Failure Nurse per 100,000 population. This service level was recommended in the Heart Failure Standards adopted by the British Cardiac Society in 2004, and those of the European Society of Cardiology 2012 and this figure was utilised for the Management of Coronary Heart Disease – A national clinical and resource impact assessment (SIGN 2007b).

The minimum recommendation of 1 nurse to 100,000 population (SIGN 2007b) was originally applied across NHS Scotland regardless of Health Board boundaries. The more realistic modelling in the first SHFNF Review 2008 (and endorsed by Audit Scotland 2012), recommended a minimum of 52.2 WTE posts to achieve the minimum ratio while allowing for working boundaries between NHS Board areas. The 47.17 WTE current posts in Scotland therefore falls short by 10% of the SIGN 2007 minimum recommendation.

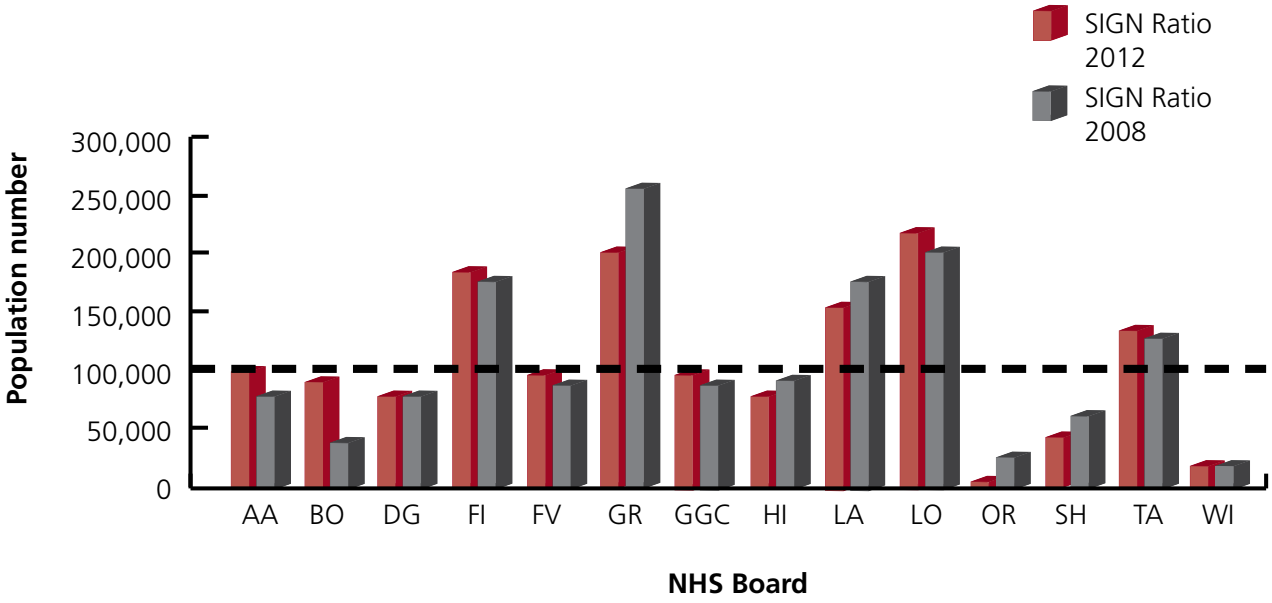


Fig. 6: SIGN Ratio (2007b) of 1 Specialist Heart Failure Nurse per 100,000 population in 2008 and 2012, by NHS Board

Applying the recommended ratio across NHS Boards in 2008 highlighted some significantly under-resourced areas. Unfortunately in 2012 this continues to be evident with 5 NHS Boards markedly exceeding the 1:100,000 ratio (Fife, Grampian, Lanarkshire, Lothian and Tayside). Where the ratio is exceeded and Specialist Heart Failure Nurse services are operating beyond maximum capacity, it will inevitably have the potential to negatively impact on the quality of service provided.

Remote & rural considerations

The ratio incorporated in guidelines does not take into account issues of remote and rural populations, which are particularly pertinent to services operating outwith the central belt and in the Highlands and Islands; for example, NHS Highland covers an area of 33,028km2 (41% of NHS Scotland) and therefore travel time for home visits and clinics will inevitably reduce capacity. These Boards will therefore need higher nurse/population ratios in order to be able to deliver an adequate service.

The Scottish Executive Urban Rural Classification is used to determine the allocation of funding to each NHS Board in respect of the challenges of serving a remote and rural community (NHS Scotland Allocation Committee 2007).

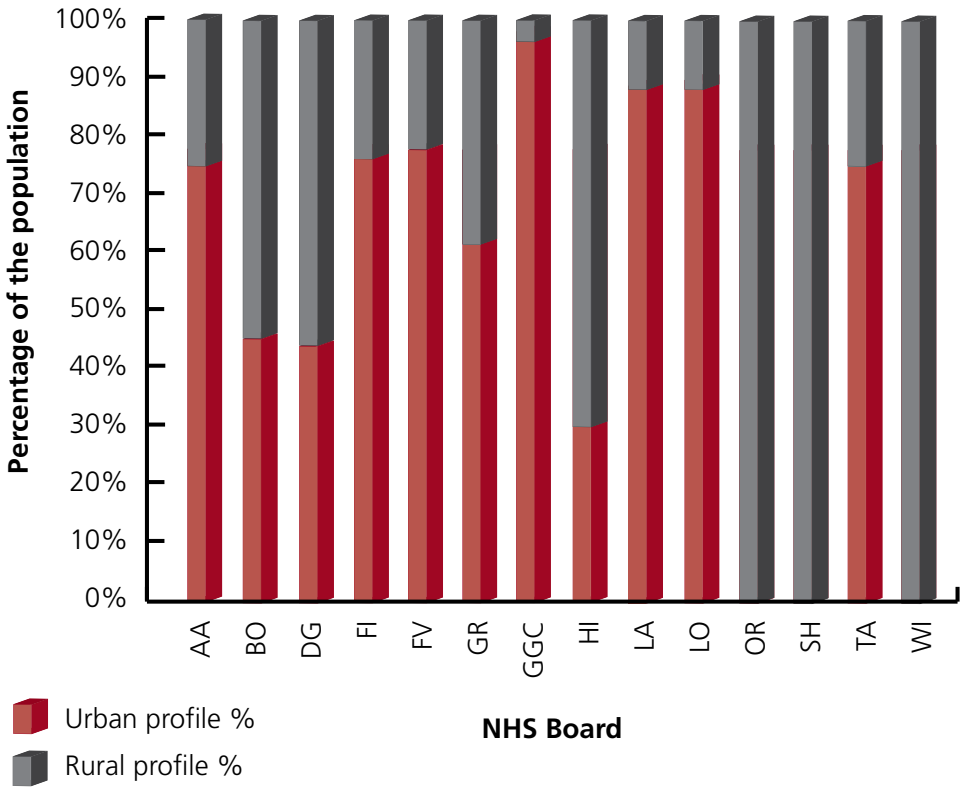


Fig. 7: Urban/rural profiles by NHS Board (Scottish Government 2012)

Scotland is geographically diverse and each Health Board has a different urban/rural profile, each setting their own challenges for Specialist Heart Failure Nurses. Figure 7 demonstrates the potential impact of serving a remote and rural caseload and highlights that this is a particular consideration when reviewing the workload of the Island Boards (Orkney, Shetland and Western Isles) and also Highland and Dumfries & Galloway.

Impact of deprivation

As well as incidence and mortality from heart disease being higher in the more deprived areas of Scotland (Audit Scotland 2012), we also know that patients often present as more complex cases with significant co-morbidities (France et al 2012). The onset of multi-morbidity occurred 10-15 years earlier in people living in the most deprived areas compared with the most affluent (Barnett et al 2012). This is of particular relevance to Greater Glasgow & Clyde as the area with the highest level of overall deprivation in Scotland.

Between 2006 and 2009 the Scottish Index of Multiple Deprivation data demonstrated that Ayrshire & Arran was the Health Board with the biggest increase in deprived datazones, increasing from 16% to 20.6% of datazones in the 15% most deprived zones in Scotland (SIMD 2009). Forth Valley and Tayside have seen the biggest reductions; Greater Glasgow & Clyde has also seen a reduction but remains the NHS Board with the highest level of deprivation overall, with a third of its datazones in the 15% most deprived and containing half of the deprived datazones in Scotland.

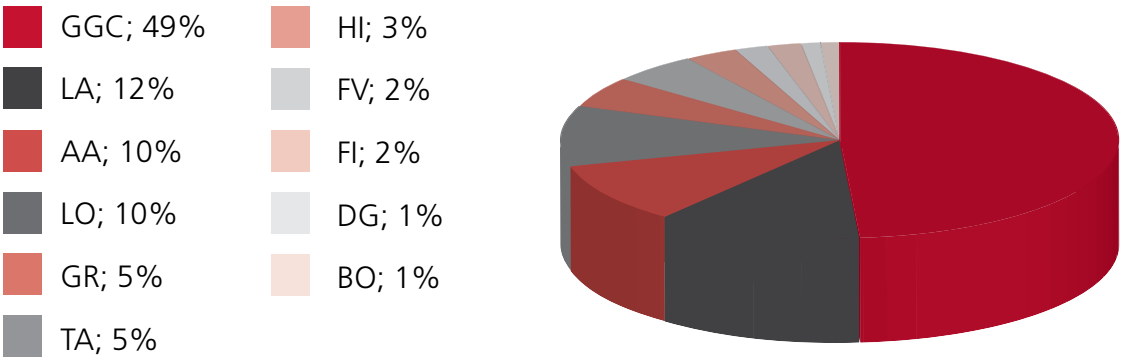


Fig. 8: Scottish Index of Multiple Deprivation data 2009, showing the distribution of the most deprived datazones, by NHS Board

It should be noted that due to a low population density, the Island Boards (Orkney, Shetland and Western Isles) do not register in the SIMD categorisation.

Caseload distribution

Since the last review in 2008, Specialist Heart Failure Nurses have reported services at or over capacity in most areas. This is reflected by the growth in individual caseloads (number of patients), which is apparent when comparing the 2008 and 2012 reported figures.

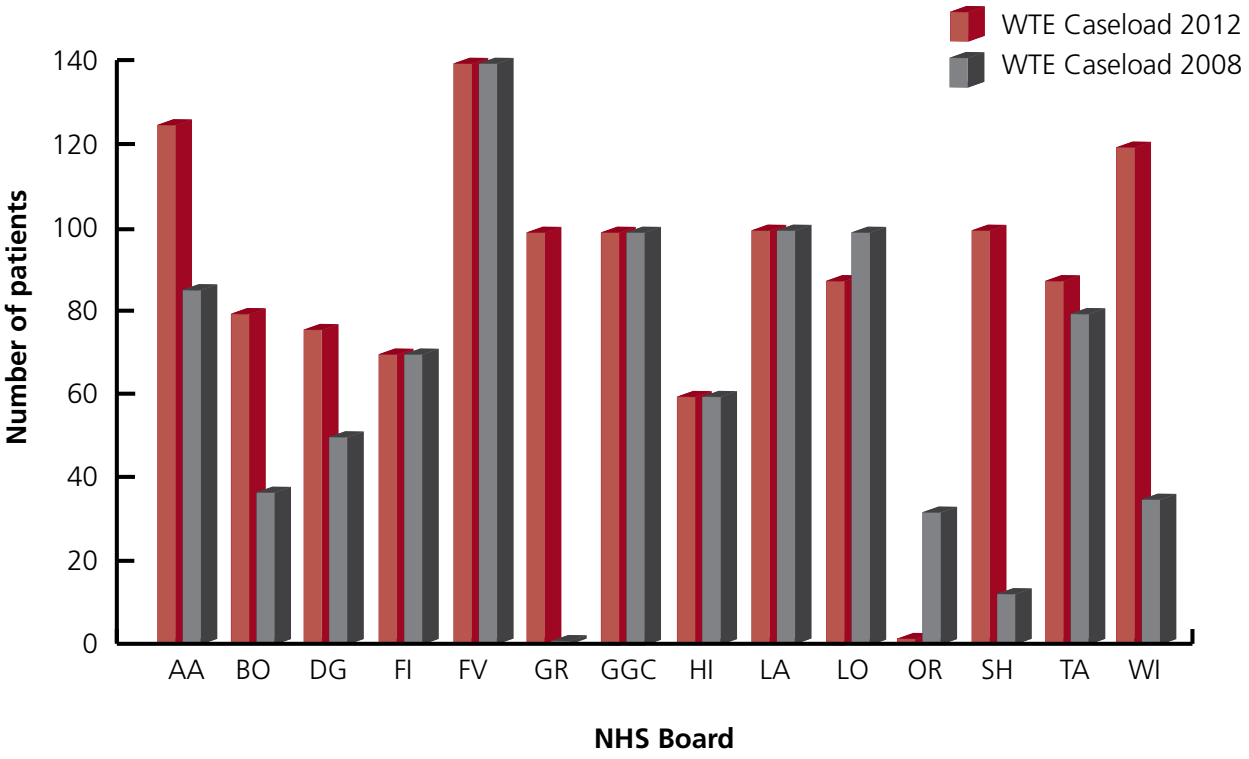


Fig. 9: Average caseloads per WTE Specialist Heart Failure Nurse post in 2008 and 2012, by NHS Board

Caseloads (which is a reflection of the average number of patients managed by a WTE Specialist Heart Failure Nurse at any particular time), have increased in 6 of the 14 NHS Boards, with the largest increase in the Western Isles (a fledgling service in 2008), with an increase from 35 to 120 patients. Increases are also seen in more established services, such as Ayrshire & Arran (established 2004) and Dumfries & Galloway (established 2002). Caseload is a reflection of workload of the individuals within a service and although in some circumstances also reflects the changing models of provision (e.g. more reliance on clinics in the Forth Valley service), the increases also correlate with the rising prevalence of heart failure and the efforts of the services to meet demand.

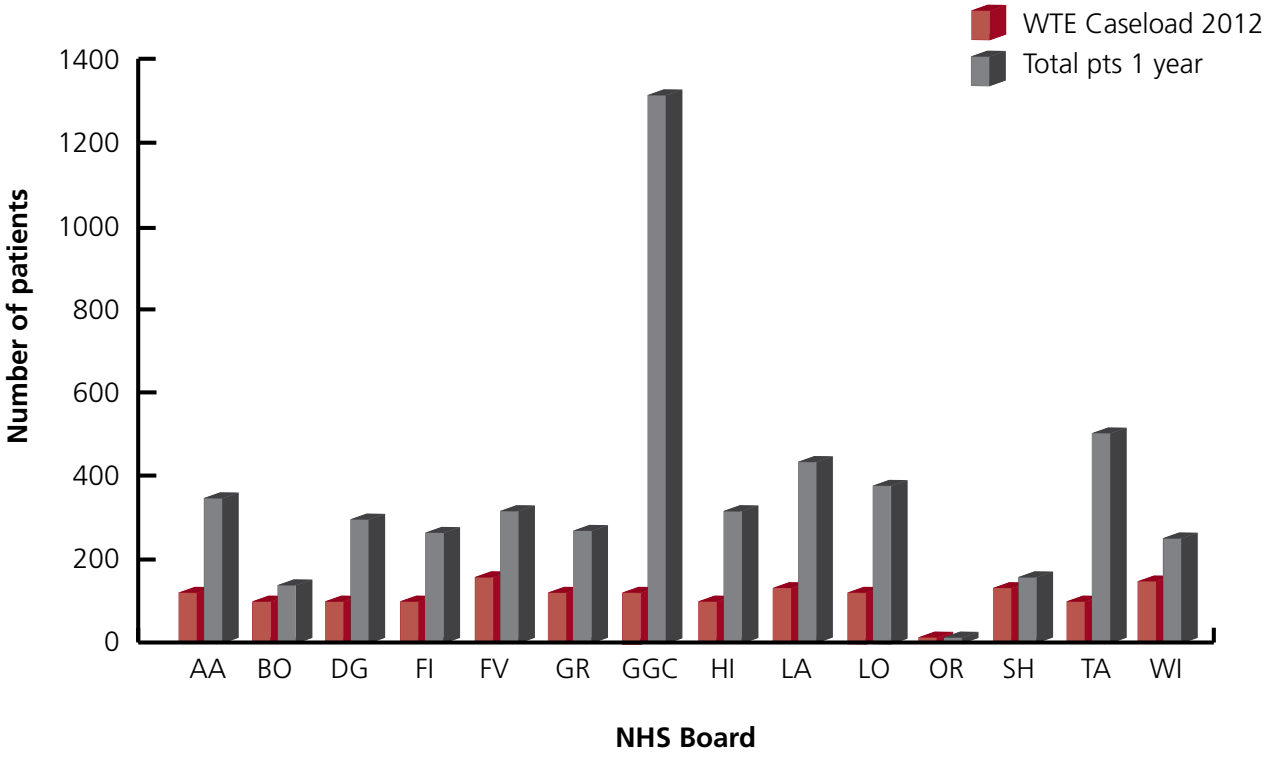


Fig. 10: Average caseload per WTE Specialist Heart Failure Nurse post in the context of total patients within the service, by NHS Board

A study evaluating the role of Specialist Heart Failure Nurses found an average active caseload of around 60 patients and established this as a recommended level (University of York 2008). This recommendation is based on a caseload comprising mostly newly identified patients, with a high level of support and information needs and with active medication titration in progress. Where the majority of the caseload comprised patients at a terminal phase and/or the frail elderly, manageable caseloads could be as low as 40 patients. Where patients were referred by cardiology consultants, stabilised and simply required ongoing review and monitoring, manageable caseloads could be as high as an average of 100 patients (University of York 2008).

Based on the information available from our membership as to working methods and caseload profile and published evidence, the SHFNF would support a recommendation of an average caseload of 60 patients, rising to 100 where a clinic model was predominantly in use.

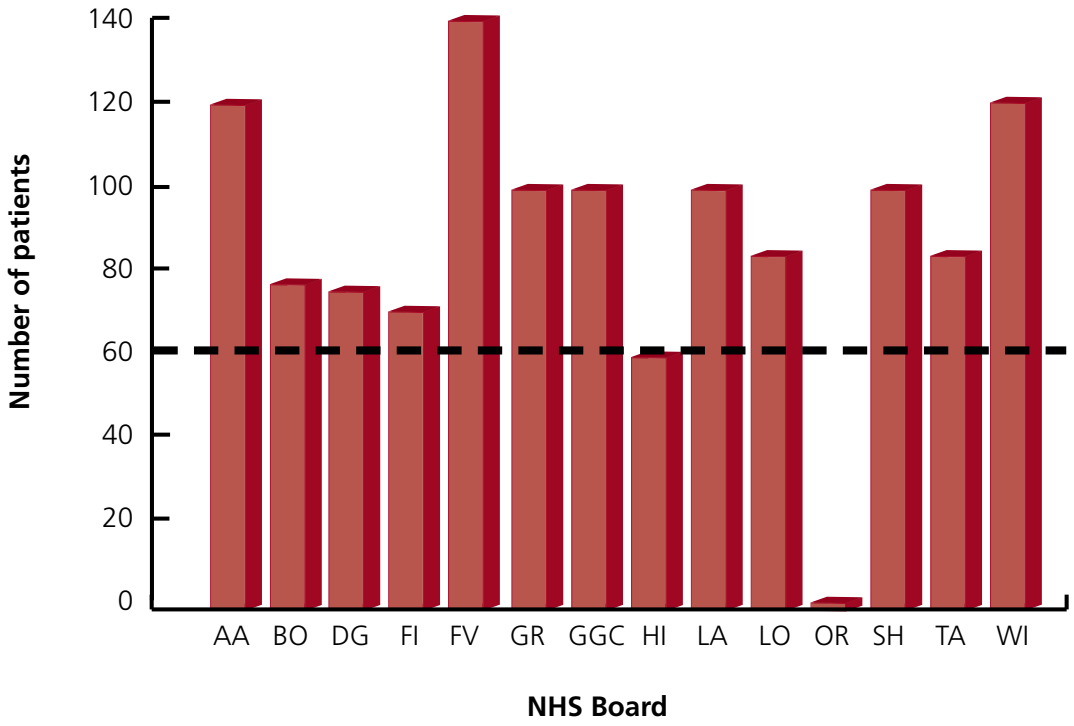


Fig. 11: Recommended level of 60 patients, applied to the average caseload per Whole Time Equivalent (WTE) Specialist Heart Failure Nurse, by NHS Board

In Scotland, nearly all existing services exceed this 60 patient average caseload recommendation. In some Boards the model of service delivery is predominantly secondary care clinic based, which reduces travel time e.g. Forth Valley, or operating on a community clinic model e.g. Ayrshire & Arran. In these Boards it would be reasonable to apply the 100 patient caseload recommendation, although it should be noted that these Boards also exceed this higher level, with average caseloads of 140 and 130 respectively.

NHS Highland falls within the 60 patient caseload recommendation, although high levels of rurality and therefore long travel times impact on the maximum potential caseload. Although similar considerations apply to the Western Isles, which has one of the highest caseload averages (120 patients), there are concerns about sustainability of service provision at this level.

Although varying models of service delivery and the inclusion of clinic options in most Boards may account for some of the high average caseloads, the general indication would be that the majority of services are operating at an unsustainable level which leaves little or no time for additional activities e.g. delivery of primary and secondary care education.

Administrative support

In 2007, a national recommendation regarding administrative support for Specialist Heart Failure Nurse services was issued:

'In order to provide comprehensive post-discharge services up to 50 nurses and 10.5 administrators were estimated to be required to allow symptomatic heart failure patients to receive nurse led home based services' (SIGN 2007b).

This minimum recommendation of 10.5 WTE, equates to a total of 393.75 hours of administrative support across Scotland (not taking account of NHS Board boundaries). The current level of administrative support for Specialist Heart Failure Nurse services in Scotland is 8.85 WTE with the total number of hours 332 (84% of the recommended minimum level).

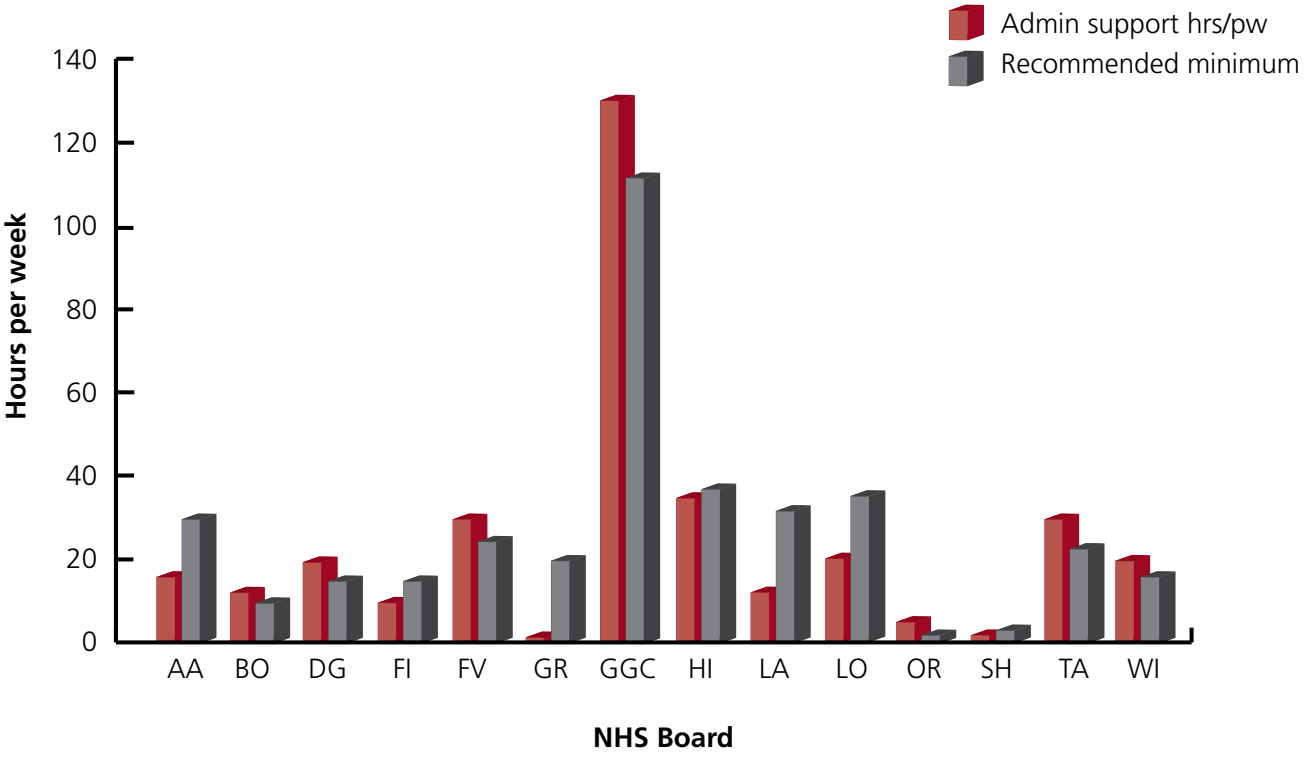


Fig. 12: Hours per week of administration support available to each Specialist Heart Failure Nurse service, by NHS Board

Two Health Boards (Grampian and Shetland) reported no available administrative support. (At the time of writing, Orkney does not have a Specialist Heart Failure Nurse service). The hours of administrative support does not necessarily correlate with the level of patient caseload. For example, Lanarkshire, which has the third highest caseload (400 patients per year) only have 13 hours of administration support per week. It should be noted that even when the level exceeds that of the minimum recommendation, the level may still not be adequate for the reality of the support required by that service e.g. Greater Glasgow & Clyde who report an ongoing challenge of valuable clinical time being diluted with routine administration tasks.

Unfortunately there is no accepted formula on which to judge a suitable level of administration support. SHFNF members report a wide variation in the amount, availability and the quality of support offered to their service. The key liaison role taken on by Specialist Heart Failure Nurses creates a significant administrative burden by coordinating referrals, updating the multi-disciplinary team and ensuring appropriate documentation and communication of care. Where the specialist team is operating without an appropriate level of administrative support, a significant amount of their time is diverted from patient care and/or educational initiatives.

Educational provision

Only 8 of the Specialist Heart Failure Nurse services are currently in the position to support or lead educational initiatives out with their team. A further 4 services reported that they were able to offer limited ad hoc educational support with the remaining 2 services having no capacity at all. Education and the need to share their skills and experience is an area that Specialist Heart Failure Nurses are passionate about. An ageing population along with an already high prevalence of heart failure in the community heralds a continuation of the increase in caseloads and demands that specialist services are experiencing.

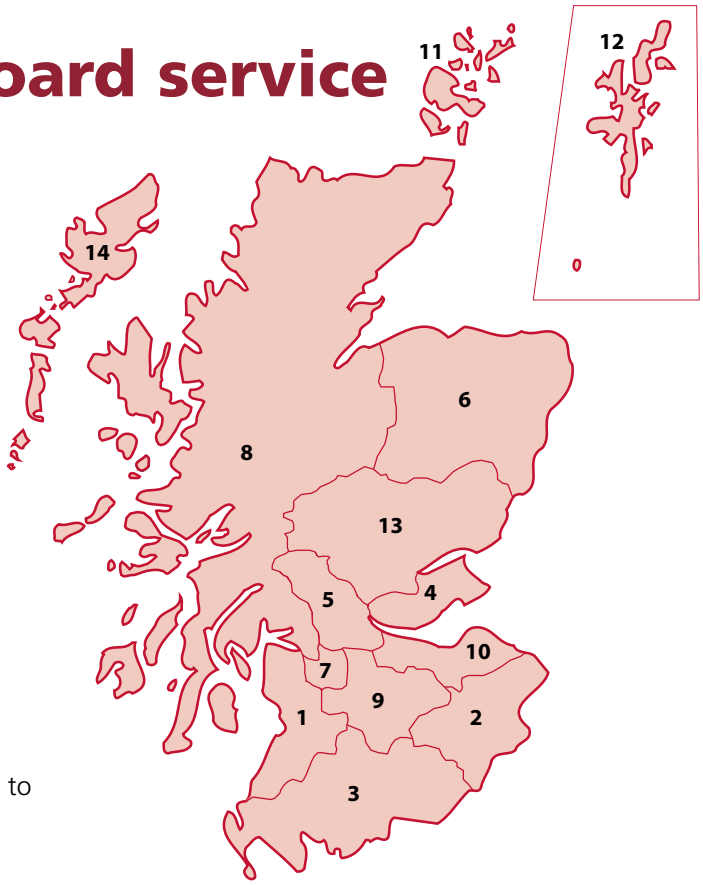
The role of the Specialist Heart Failure Nurse is to care for the most complex cases where their expertise is most effective. Annually, an average GP practice with a list of 10,000 patients may refer approximately 20 patients with suspected heart failure and approximately 70 patients with a confirmed diagnosis of heart failure to a heart failure team (Pattenden 2008). A typical practice will also have between 90 and 100 patients on their Heart Failure Register; in the case of a very elderly population, it may be more. (Pattenden 2008)

In 2012, Audit Scotland stated *'heart failure nurses reported that they are receiving many referrals of patients who, if supported sooner by other services, may well not have deteriorated to the level of requiring specialist support. Given the pressure on these specialist services there is limited capacity to deliver education and share their skills and expertise with other community staff to ensure heart failure patients are receiving the support they need'*.

For the benefits of a Specialist Heart Failure Nurse service to be sustainable and have the optimal impact, capacity is required in order to lead and participate in educational initiatives which promote the safe and effective management of people living with heart failure across primary and secondary care teams.

Individual NHS Board service profiles 2012

1. **Ayrshire & Arran**
2. **Borders**
3. **Dumfries & Galloway**
4. **Fife**
5. **Forth Valley**
6. **Grampian**
7. **Greater Glasgow & Clyde**
8. **Highland**
9. **Lanarkshire**
10. **Lothian**
11. **Orkney**
12. **Shetland**
13. **Tayside**
14. **Western Isles**

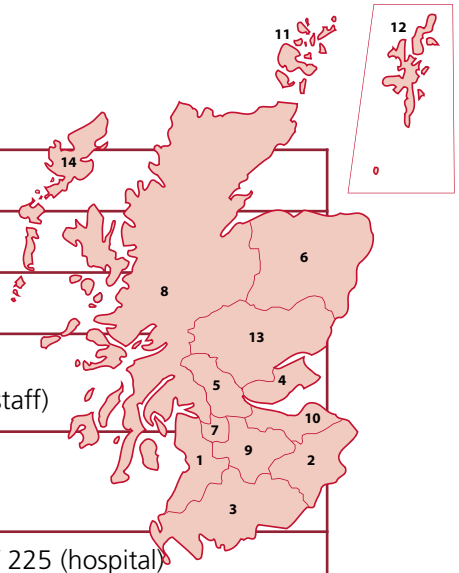


The 'free text' within individual profiles has been submitted by each service and forms the narrative to accompany the figures, highlighting the successes and challenges that they consider significant.

Accompanying notes:

- Total Board Population taken from General Registrar for Scotland 2011 figures
- Urban/Rural classification taken from Scottish Government 2012, Urban Rural Classification 2011-2012 Population Tables.
- SIGN Ratio is the 2007 minimum recommendation of 1 Specialist Heart Failure Nurse (SHFN) per 100,000 of population (applied to NHS Board)
- Average caseload is based on an average day for a WTE SHFN in that NHS Board
- Individual patients managed by service in 1 year is a reflection of the average workload of each service within a 12 month period
- Service provision is an estimate of the proportion of patients receiving home visits and those receiving other methods of support (the standard model is home visits or clinic appointments)
- Provision for HF-PEF (Heart Failure with Preserved Ejection Fraction) reflects whether the service is operating out with the traditional model of supporting patients with Left Ventricular Systolic Dysfunction (see Section One 'Heart Failure' for more detail on the types of heart failure)
- Administrative support per week is calculated on an average week with the maximum support available to that service
- Providing education to non-specialist staff reflects whether the service has capacity to share expertise and skill with non-specialists within the NHS Board area
- Doctor with specialist interest in heart failure is the availability of an individual with a heart failure remit and reflects the level of clinical support available to the service
- Cardiac rehabilitation available is simply 'yes' or 'no' and the number seen reflects the total referrals for patients with heart failure in one year
- Access to psychological support referral pathway reflects the ease with which referrals can be made within that NHS Board area.

1. Ayrshire & Arran



Date service commenced	May 2004
Total Board Population	366,860
Urban/Rural	78% / 22%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	4 WTE (7 staff) 2008 – 5 WTE (6 staff)
SIGN Ratio	1:91,715 2008 – 1:73,290
Ave. caseload per post	125 (community) / 225 (hospital)
Individual patients managed by service (average year)	348 patients
Service provision	Home visits 80% / Clinic appointments 20%
Provision for HF-PEF	No
Administration support per week	18.75 hours (across service)
Providing education to non-specialist staff	Yes – informal basis to non-specialist staff
Doctor with specialist interest in Heart Failure	1 Consultant Cardiologist (non-specialist)
Cardiac Rehabilitation available/number seen	Yes – 80 patients in total
Access to psychological support referral pathway	Inadequate (currently recruiting to clinical post)

Notes on current service provision:

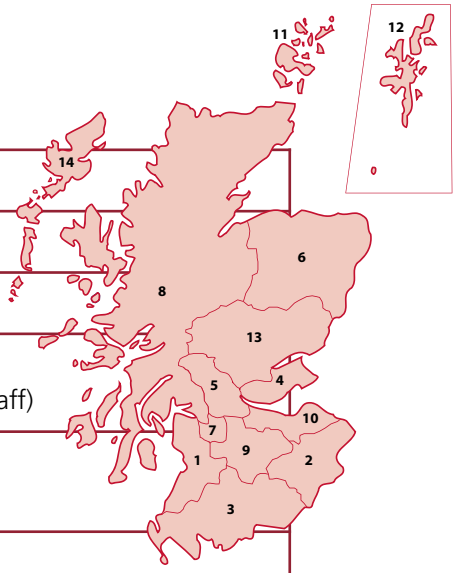
Three full-time posts are based in the community to follow-up patients discharged from secondary care and four advanced specialist nurses are based within the acute setting; their posts also cover Chest Pain Assessment, outpatient Rapid Access Chest Pain clinics and Cardiac Rehabilitation. Most referrals are from secondary care, although 30 were also received direct from GPs.

Funding in comparison to 2008: The service is core funded by the NHS with adequate provision, although the previous BHF Post of Palliative Care Specialist Nurse did not receive ongoing funding. The service is undergoing a process of succession planning for the Specialist Nurse posts.

Challenges: The service is facing rising caseloads and differing methods of management are predicted to be challenges for the future. A replacement lead for the established Clinical Psychology service is awaited.

Development opportunities: A new database was recently implemented within the service and the specialist nurses are leading on the implementation of the HF Bundle across the NHS Board. New projects currently include tele-monitoring and the administration of diuretics (through a BHF funded secondment for 2 years). A new ICD pathway is also in the process of being implemented which will have the potential to impact on patients and the service.

2. Borders



Date service commenced	April 2007
Total Board Population	112,870
Urban/Rural	47% / 53%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	1.3 WTE (3 staff) 2008 – 2.5 WTE (3 staff)
SIGN Ratio	1:86,823 2008 – 1:44,499
Ave. caseload per post	80 (community)
Individual patients managed by service (average year)	140 patients
Service provision	Home visits 75% / Clinic appointments 25%
Provision for HF-PEF	No
Administration support per week	15 hours (across service)
Providing education to non-specialist staff	Yes, but only on an ad hoc basis to ward staff, GPs
Doctor with specialist interest in Heart Failure	None
Cardiac Rehabilitation available/number seen	No
Access to psychological support referral pathway	Inadequate

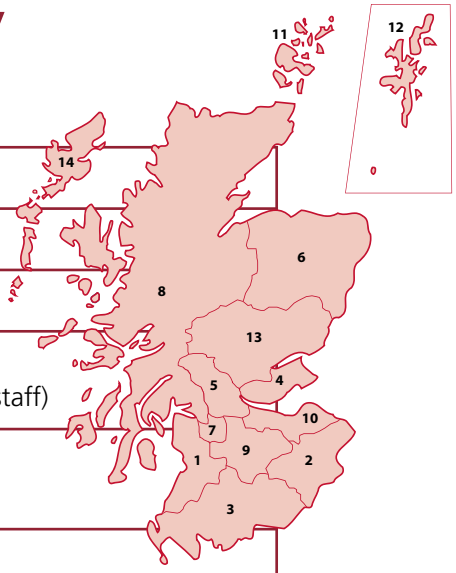
Notes on current service provision:
Large rural area with significant travel times between patient visits. One Heart Failure Nurse Specialist post and two Cardiac Specialist Nurses, who also provide support to the service with a small heart failure patient caseloads.

Funding in comparison to 2008: In 2008, NHS Borders had 2.5 WTE posts funded by the BHF (no longer funded by BHF). Health Board due to take on BHF funded post. Only 0.8 WTE now funded by NHS Borders but funding not secured and only at present until end March 2013. The Cardiac Specialist Nurses who support service are core funded by NHS Borders, but due to uncertainty of funding with the Heart Failure Specialist post, the service has been unable to develop.

Challenges: Uncertainty in ongoing funding and staff changeover in the cardiac services has been unsettling and has added to overall workload. Unable to provide cover to review patients when staff are on annual leave.

Development opportunities: Unfortunately the heart failure service has been unable to develop as we would have liked it to due to financial constraints and staffing, but we hope to initially develop more formal educational sessions within the community.

3. Dumfries & Galloway



Date service commenced	April 2002
Total Board Population	148,190
Urban/Rural	46% / 54%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	2 WTE (2 staff) 2008 – 2 WTE (4 staff)
SIGN Ratio	1:74,095 2008 – 1:74,015
Ave. caseload per post	75 patients
Individual patients managed by service (average year)	268 patients
Service provision	Telephone contacts 41% / Home visits 38% / Hospital visits 13% / Clinic appointments 8%
Provision for HF-PEF	No
Administration support per week	20 hours (across service)
Providing education to non-specialist staff	Yes
Doctor with specialist interest in Heart Failure	None
Cardiac Rehabilitation available/number seen	Yes – 33 in HF exercise classes and 20 in mainstream CR
Access to psychological support referral pathway	Inadequate (only available on an ad hoc basis)

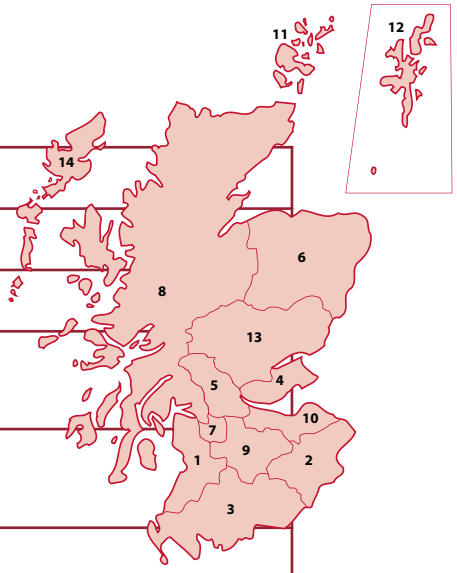
Notes on current service provision:
Covering both primary and secondary care, although initially employed to cover the community, this has gradually developed to incorporate the acute site. With 2,380 square miles and two District General Hospitals, D&G is a vast area with both urban and rural caseloads. The service is provided on the Scotland/England border and therefore some patients with Scottish GPs are nearer English referral centres and concurrently some referrals are also taken from Northern England.

Funding in comparison to 2008: Core funded service, fully integrated into NHS Dumfries & Galloway provision.

Challenges: Increased presence and demand from acute hospital setting for Heart Failure Nurse Service input and advice but with no additional resources.

Development opportunities: Team leading on the Scottish Patient Safety Program [SPSP] work. A Heart Failure patient support group (affiliated to Chest Heart & Stroke Scotland), supported by nurses and physiotherapist is now up and running and Telemonitor provision (pilot) for ten patients, led and managed by the team has been launched. Patients are referred to specialist physiotherapist with class and home based rehabilitation programmes available as well as links to leisure services.

4. Fife



Date service commenced	August 2004
Total Board Population	364,945
Urban/Rural	79% / 21%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	2 WTE (2 staff) 2008 – 2 WTE (2 staff)
SIGN Ratio	1:182,473 2008 – 1:179,429
Ave. caseload per post	70 (community)
Individual patients managed by service (average year)	238 patients
Service provision	Home visits 80% / Clinic appointments 20%
Provision for HF-PEF	Yes – cardiologist referral with management plan in place
Administration support per week	9 hours (across service)
Providing education to non-specialist staff	Yes – 1 hour sessions to GP surgeries raising awareness of service pathway and refresher on heart failure management
Doctor with specialist interest in Heart Failure	1 Consultant Cardiologist (specialist interest)
Cardiac Rehabilitation available/number seen	Limited – no referral pathway
Access to psychological support referral pathway	Inadequate (waiting list of up to 6 months)

Notes on current service provision:

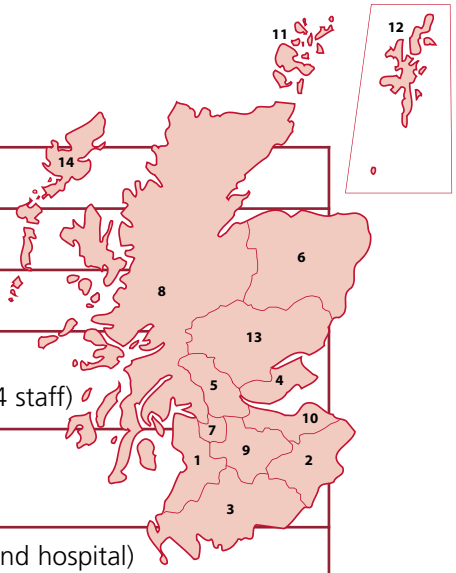
In 2010, the service moved from management by the Acute Operating Division to within Primary Care. Service redesign is ongoing to ensure that the service is being utilised to maximum effect. An increase in telephone consultations and developing locality clinics allows us to continue to see patients close to their homes and cuts down time and money (mileage) spent travelling to home visits. By developing closer working relationships and sharing the more stable caseload with the vascular teams in the CHPs, the service can see more patients. A lot of work has been carried out to develop and implement the heart failure care bundle, with MCN support.

Funding in comparison to 2008: Core funded by NHS Fife.

Challenges: Despite increasing demand, we are able to keep a manageable caseload by transferring the care of more stable patients to the vascular services in the CHPs. Our case load number does not reflect the true amount of referrals coming into and being discharged from the service.

Development opportunities: We are opening referrals to other types of heart failure e.g. HF-PEF and inoperable valve problems (if referred by a cardiologist with a management plan). Widening the criteria has not overwhelmed the service and input from the service has reduced hospital admissions and improved the patient's quality of life. We are participating in a 2 year Telehealth pilot and a multidisciplinary heart failure clinic for both new and existing referrals.

5. Forth Valley



Date service commenced	December 1999
Total Board Population	293,386
Urban/Rural	80% / 20%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	3 WTE (4 staff) 2008 – 3.2 WTE (4 staff)
SIGN Ratio	1:97,795 2008 – 1:89,392
Ave. caseload per post	140 (community and hospital)
Individual patients managed by service (average year)	300 patients
Service provision	Home visits 20% / Clinic appointments 80%
Provision for HF-PEF	No
Administration support per week	30 hours (across service)
Providing education to non-specialist staff	Yes – Secondary care: individual and group teaching with staff nurses and healthcare assistants in cardiology wards and clinics; Primary care: create meetings
Doctor with specialist interest in Heart Failure	Yes – 1 Consultant
Cardiac Rehabilitation available/number seen	Yes – 50 patients per year
Access to psychological support referral pathway	Adequate

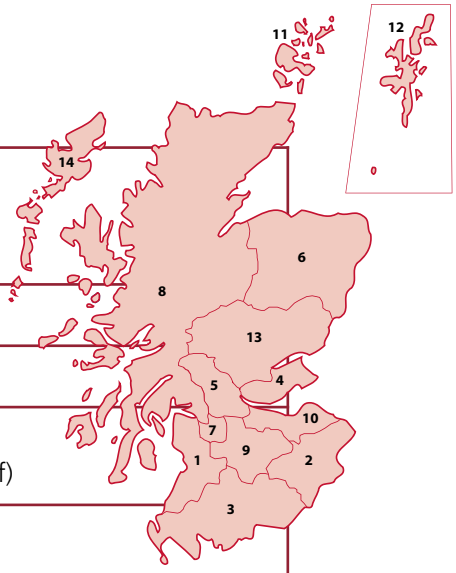
Notes on current service provision:
Manage patients with LVSD and symptomatic Heart Failure. Referrals received from wards, Cardiology and other clinics, Open Access Echocardiography and General Practice. Actively discharge patients once optimised and stable; liaise with SNAHFS as appropriate.

Funding in comparison to 2008: Core funded by NHS Forth Valley

Challenges: Only one nurse undertakes outreach visits for Forth Valley. Managing in-patient workload with out-patient clinics and unpredictability of help-line calls all stretches service provision. Increasingly complex patients, particularly those with significant renal dysfunction. Unable to respond to demand to review patients with HF-PEF.

Development opportunities: HF nurses, in conjunction with consultants, implement evidence-based medicine in patients admitted with decompensation using the HF bundle and a holistic approach incorporating discharge planning. Access to Day Medicine Unit for patients who require IV diuretics. Provide pre-op assessment and education for patients undergoing implantation of a cardio-defibrillator [ICD].

6. Grampian



Date service commenced	March 2004 (break in service 2007-2009)
Total Board Population	550,620
Urban/Rural	64% / 36%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	2.65 WTE (4 staff) 2008 – 2 WTE (4 staff)
SIGN Ratio	1:207,781 2008 – 1:264,944
Ave. caseload per post	100 patients (community)
Individual patients managed by service (average year)	250 patients
Service provision	Home visits 80% / Clinic appointments 20%
Provision for HF-PEF	No
Administration support per week	3 hours (across service)
Providing education to non-specialist staff	Yes – limited to primary care sessions within Aberdeen City
Doctor with specialist interest in Heart Failure	None
Cardiac Rehabilitation available/number seen	No
Access to psychological support referral pathway	None

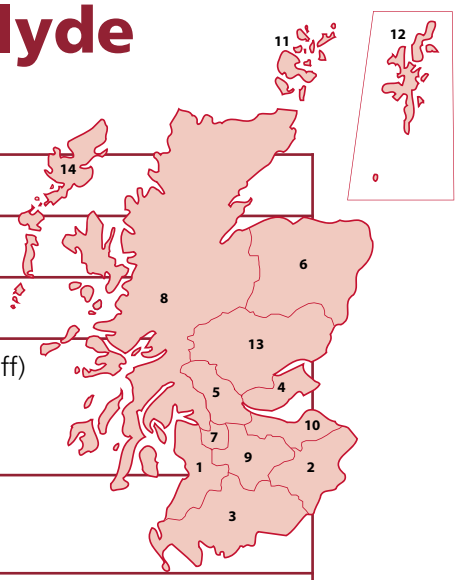
Notes on current service provision:
The service has been operating in a fragmented manner with part-time provision in Aberdeen City and South/Central and North Aberdeenshire and there is no consistent management structure from which to develop the service.

Funding in comparison to 2008: Funding is an ongoing issue; currently guaranteed for only a further two years 2012-2014, in both Aberdeen City and Aberdeenshire. Following a service break 2007-2009, service was recommenced through BHF funded period (2009-2011).

Challenges: The inadequate administration support impacts on the service as Specialist Nurses take on the majority of the administration work.

Development opportunities: The nurses have worked hard to resurrect referral pathways following the break in service and are keen to share their knowledge with primary care colleagues and improve sustainability of provision against high caseloads and high demand in a challenging geographical area.

7. Greater Glasgow & Clyde



Date service commenced	August 1999
Total Board Population	1,203,870
Urban/Rural	98% / 2%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	14.62 WTE (17 staff) 2008 – 16.3 WTE (20 staff)
SIGN Ratio	1:82,344 2008 – 1:73,103
Ave. caseload per post	100 (community)
Individual patients managed by service (average year)	1,300 patients
Service provision	Home visits 35% / Clinic appointments 65%
Provision for HF-PEF	No
Administration support per week	129.75 hours (across service)
Providing education to non-specialist staff	Yes
Doctor with specialist interest in Heart Failure	5 Cardiologists
Cardiac Rehabilitation available/number seen	No
Access to psychological support referral pathway	None

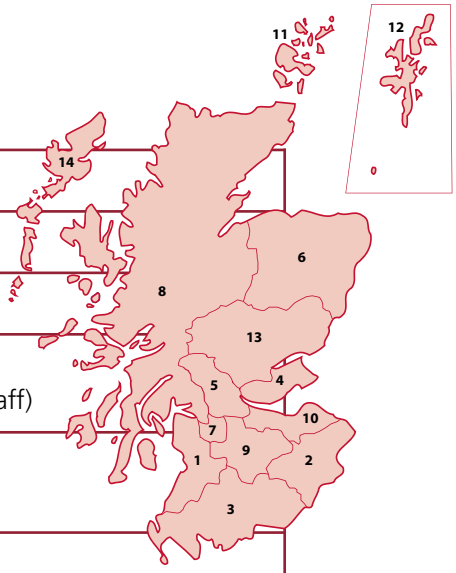
Notes on current service provision:
Local enhanced service and diagnostic pathway, recently staggered launch over Board area. This will lead to greater interaction of referrals and discharges between HF service and primary care; efficacy being evaluated. Direct access echo route provided. Despite a reduction in the WTE posts, length of stay and admissions were reduced in 2011. Patient education programme provided by 3 WTE posts.

Funding in comparison to 2008: Substantive funding provided by NHS Greater Glasgow & Clyde. BHF providing 0.5 WTE funding over 2 years for IV Diuretic project.

Challenges: Due to limited rehabilitation resources, currently no class offered to patients with heart failure; MCN acknowledged that this should remain on agenda and as a group remains an aspiration. Increasing time demands from Caring Together palliative project with no increase in WTE posts. Community diuretic programme high demand of time per patient. Ongoing development of Electronic Patient Records impacts on nurse time and restricted ability of the service to provide full Early Supported Discharge [ESD] approach.

Development opportunities: Extending scope of IV diuretic role to provide ESD and day care approach may prove more time and cost efficient. Ongoing review of what can realistically be sustained from palliative care provision. Web based management system under development, which will allow greater flexibility to work between acute and community sites and aims to provide wireless home based/community working options.

8. Highland



Date service commenced	November 2006
Total Board Population	310,830
Urban/Rural	31% / 69%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	4.5 WTE (8 staff) 2008 – 3.4 WTE (7 staff)
SIGN Ratio	1:69,073 2008 – 1:78,385
Ave. caseload per post	60 (community)
Individual patients managed by service (average year)	289 patients
Service provision	Home visits 70% / Clinic appointments 30%
Provision for HF-PEF	No
Administration support per week	31 hours (across service)
Providing education to non-specialist staff	Limited – training programme for community staff
Doctor with specialist interest in Heart Failure	2 Consultants with interest
Cardiac Rehabilitation available/number seen	Limited – sporadic access from individual physiotherapists
Access to psychological support referral pathway	None

Notes on current service provision:

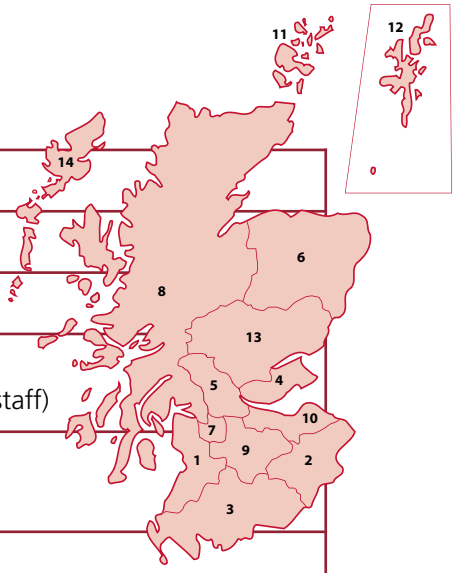
The service is strong at the moment and we appear to be meeting local and national targets. Due to our geography we frequently provide telephone contact with patients who live in remote and rural areas as we cannot see them as regularly as we would like. We are also working with community teams to provide a more structured approach to their care. Patients not suitable for the service are offered education booklets/ongoing support via the newsletter and forum meetings (in partnership with CHSS). The service within Dunoon and Cowal is in its infancy, Mid Argyll referrals are picking up, but Kintyre has been slow; the reasons are unclear.

Funding in comparison to 2008: Following BHF funding from 2006, we are about to move over to full funding from the Board.

Challenges: Providing an equitable service in the Highlands is challenging. We are often faced with being unable to see patients straight from discharge due to limited time staff have within that area. Obtaining clinic space is hard, transport issues can be a problem; with the need for ferries an island service is challenging.

Development opportunities: Trying to implement the SPSP bundle (2 hospitals), which in theory should help referral rates has been challenging. We are providing training for community nurses in the hope that stable patients can be managed locally. We have also looked at Telehealth filling this gap; unfortunately we have had issues with the NHS server and therefore been unable to progress.

9. Lanarkshire



Date service commenced	October 2004
Total Board Population	562,477
Urban/Rural	89% / 11%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	3.6 WTE (4 staff) 2008 – 3 WTE (4 staff)
SIGN Ratio	1:156,244 2008 – 1:186,046
Ave. caseload per post	100 (community)
Individual patients managed by service (average year)	400 patients
Service provision	Home visits 80% / Clinic appointments 20%
Provision for HF-PEF	No
Administration support per week	13 hours (across service)
Providing education to non-specialist staff	No – no capacity
Doctor with specialist interest in Heart Failure	2 Consultants with interest
Cardiac Rehabilitation available/number seen	Limited (one site) – 3 patients
Access to psychological support referral pathway	None

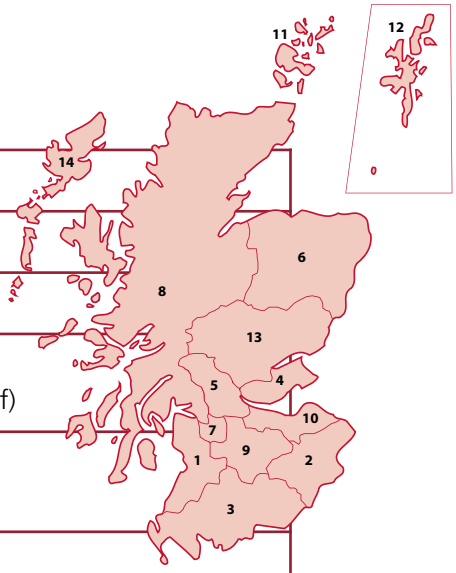
Notes on current service provision:
Challenging area, both geographical and due to large areas of deprivation and multiple co-morbidities with a high incidence of alcohol and drug dependence in young people, all of which results in educational challenges due to lack of insight. Numbers are fairly static despite discharges and deaths and new referrals are regularly received; each site is at optimal capacity. Covering three District General Hospitals can at times result in a lack of cohesive decisions/discussion between consultants.

Funding in comparison to 2008: Core funded by NHS Lanarkshire.

Challenges: Running at capacity does not allow any additional time to develop sustainability of the service and leads to training issues such as prescribing courses, clinical assessment and proposed rotation of other cardiology nurses. Unable to access clinic at Wishaw General Hospital since service started (no availability in outpatient department), which would improve ability to meet demand.

Development opportunities: Three nurse prescribers in Lanarkshire (one pending results).

10. Lothian



Date service commenced	March 2002
Total Board Population	836,711
Urban/Rural	89% / 11%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	4 WTE (4 staff) 2008 – 5 WTE (5 staff)
SIGN Ratio	1:209,178 2008 – 1:200,328
Ave. caseload per post	90 (community)
Individual patients managed by service (average year)	310 patients
Service provision	Home visits 40% / Clinic appointments 60%
Provision for HF-PEF	No
Administration support per week	16-20 hours (across service)
Providing education to non-specialist staff	Limited – on request only via lectures / informal meetings / One long term cardiac conditions module delivered.
Doctor with specialist interest in Heart Failure	None
Cardiac Rehabilitation available/number seen	Yes – all patients reviewed on referral
Access to psychological support referral pathway	Adequate - all patients reviewed on referral

Notes on current service provision:

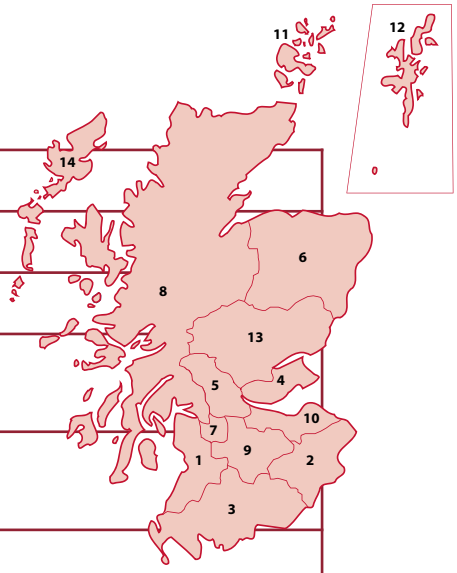
The team review patients admitted to hospital in addition to clinic and day hospital referrals. There are a small proportion of GP referrals if they are known to have heart failure due to LVSD and are at risk of admission. The service takes a case management approach due to multiple co-morbidities. The service provides locality clinics in community hospitals and GP surgeries as well as in secondary care outpatient departments. Telephone follow up is also part of the review process.

Funding in comparison to 2008: Core funding via NHS Lothian remains unchanged. BHF funding for heart failure education post finished and no further funding was provided for this post by NHS Lothian.

Challenges: To continue to deliver an education programme in the absence of a dedicated nurse. To participate in service changes, for example Telehealth/education/ increased acute care focus with no additional staff. To support the Scottish Patient Safety Programme (SPSP) within the hospital whilst primarily delivering a community based service. Caseloads are always at maximum capacity despite regular discharges and referral to community teams.

Development opportunities: Currently developing a Telehealth programme in NHS Lothian and NHS 24 for patients with heart failure. Continue to build on success of the heart failure palliative care anticipatory care plan.

11. Orkney



Date service commenced	March 2007
Total Board Population	20,110
Urban/Rural	0% / 100%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	None 2008 – 1 WTE (1)
SIGN Ratio	None 2008 - 1:19,770
Ave. caseload per post	N/A
Individual patients managed by service (average year)	N/A
Service provision	N/A
Provision for HF-PEF	No
Administration support per week	10 hours available
Providing education to non-specialist staff	Limited (on an as required basis, but limited capacity)
Doctor with specialist interest in Heart Failure	None
Cardiac Rehabilitation available/number seen	Yes – stable patients have access
Access to psychological support referral pathway	Adequate

Notes on current service provision:

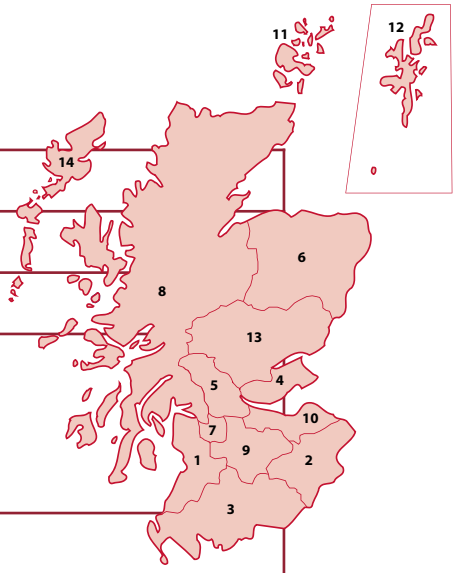
The service successfully reduced all cause admissions for patients with heart failure between 2007-10, despite the postholder having to also cover the cardiac specialist nurse role. Due to the retirement of the cardiac nurse the workload was such that the community heart failure service was withdrawn.

Funding in comparison to 2008: Funding was not continued following initial BHF funded period.

Challenges: There is 1 x WTE Clinical Nurse Specialist, who is a Heart Failure Nurse Practitioner. Advice and inpatient review available on an as required basis, but once they are discharged, there is no capacity for a community caseload. Previous experience has shown that having one post within the service is unsustainable. There is no permanent Echocardiographer post on Orkney with the services relying on a locum for diagnostic echocardiograms.

Development opportunities: Business case in progress for a new post to support the Cardiac Specialist Nurse role and the Heart Failure Liaison Service.

12. Shetland



Date service commenced	June 2005
Total Board Population	22,400
Urban/Rural	0% / 100%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	0.5 WTE (1 member of staff) 2008 – 0.3 WTE (1 member of staff)
SIGN Ratio	1:44,800 2008 – 1:72,390
Ave. caseload per post	100 (hospital/community)
Individual patients managed by service (average year)	120 patients
Service provision	Home visits 40% / Clinic appointments 60%
Provision for HF-PEF	No
Administration support per week	None
Providing education to non-specialist staff	Yes – update available to all staff annually
Doctor with specialist interest in Heart Failure	Yes – Consultant Physician with heart failure interest
Cardiac Rehabilitation available/number seen	Yes – 20 per annum
Access to psychological support referral pathway	None

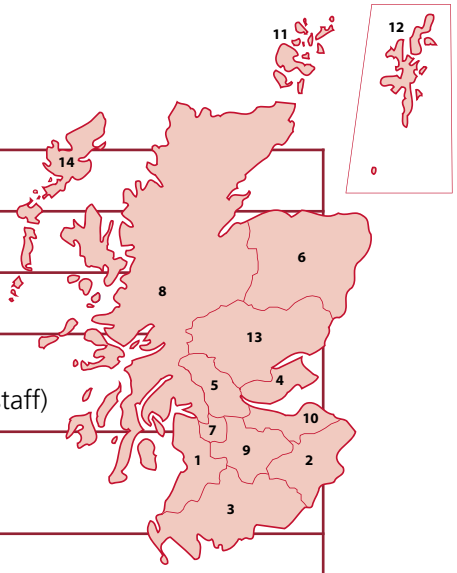
Notes on current service provision:
Challenging rural area with one half-time post covering the service.

Funding in comparison to 2008: Core funded by NHS Shetland.

Challenges: Post-holder also has roles within Cardiac Rehabilitation, Rapid Access Chest Pain service, service development and work with the Managed Clinical Network.

Development opportunities: Open access has been established for patients with heart failure within the cardiac rehabilitation service and active management of the end of life for heart failure and palliative care links is in place.

13. Tayside



Date service commenced	May 2004
Total Board Population	402,641
Urban/Rural	76% / 24%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	3 WTE (3 staff) 2008 – 3 WTE (3 staff)
SIGN Ratio	1:134,214 2008 – 1:130,546
Ave. caseload per post	90 (community)
Individual patients managed by service (average year)	515 patients
Service provision	70% Home visits / 30% Telephone follow-up
Provision for HF-PEF	No
Administration support per week	30 hours (across service)
Providing education to non-specialist staff	Yes – variety; ward/primary care, protected learning time events, Dundee University modules.
Doctor with specialist interest in Heart Failure	2 (Clinical Lead for Heart Failure and Heart Failure Specialist Consultant)
Cardiac Rehabilitation available/number seen	Yes – 25 patients per annum
Access to psychological support referral pathway	None

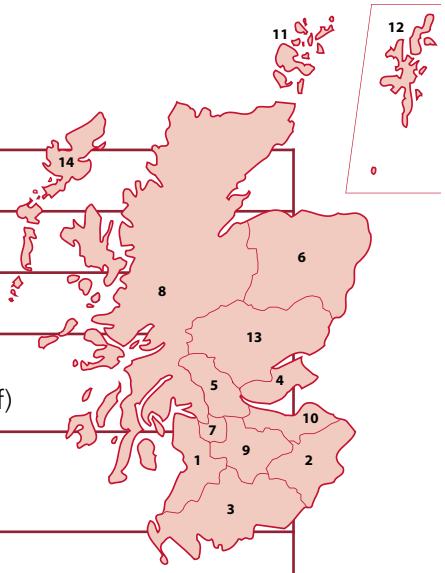
Notes on current service provision:
Providing home and telephone follow up for patients following discharge from hospital or following clinic review where they have been identified as unstable. This model of delivery supports general heart failure management and rapid response to clinical deterioration, through advancing illness to end of life support. Strong links with the palliative care team provides specialist input and seamless care in the community setting and prevention of readmissions remains a key target.

Funding in comparison to 2008: Core funded by NHS Tayside.

Challenges: Standards for review timelines post discharge are challenging due to both numbers and location and remain under evaluation. The provision of rapid response (in a rural setting), has resulted in improved cross-boundary working and improved liaison across the specialities.

Development opportunities: All three nurses in the team are Independent Prescribers and two have also completed the Palliative Care module (for heart failure) at Glasgow Caledonian University. Recent Royal College of Nursing/Office for Public Management economic analysis of the Tayside service has identified clear financial benefits that may be achieved by organisational investment in the service; this analysis is to be further explored at Cardiology Management level.

14. Western Isles



Date service commenced	April 2007
Total Board Population	26,190
Urban/Rural	0% / 100%
Specialist Heart Failure Nurse WTE Posts (actual no. staff)	2 WTE (3 staff) 2008 – 2 WTE (3 staff)
SIGN Ratio	1:13,095 2008 – 1:13,075
Ave. caseload per post	120 (community)
Individual patients managed by service (average year)	240 patients
Service provision	Home visits 30% / Hospital Clinic 40% / Community clinic 30% /
Provision for HF-PEF	No
Administration support per week	22.5 hours (across service)
Providing education to non-specialist staff	No
Doctor with specialist interest in Heart Failure	1 GPwSI
Cardiac Rehabilitation available/number seen	Yes – 20 patients per annum
Access to psychological support referral pathway	None

Notes on current service provision:

Patients are spread unevenly across the island chain with sparse population in remote and rural areas, particularly the southern isles (Uists & Barra). Many patients are in hard to reach remote areas requiring long journeys (including ferries) to home visit or clinic setting.

Funding in comparison to 2008: Substantive funding now in place for 2 WTE posts, following initial BHF funded period. BHF funded Healthcare Assistant pilot (over 2 years) post not continued.

Challenges: Elderly demographic plus remote/rural setting results in higher than 'usual' number of visits required. Cardiac rehabilitation access through Change Fund initiative for 2 years and substantive funding not confirmed from NHS.

Development opportunities: We are fortunate to have access to BNP testing (community only) but we may lose this facility as it is being reviewed due to costs. Support from the Scottish National Advanced Heart Failure Service via Tele-link, which is invaluable for the more complex cases.

SHFNF 2012 Review
Recommendations

- **Sustainable investment commitments from all NHS Boards to continue the development of the invaluable support provided by the Specialist Heart Failure Nurse services, acknowledging the need to 'spend to save' in the care of the increasing population of those living with heart failure.**

- **A nationally led and consistent approach applied to the planning and adequate resourcing of Specialist Heart Failure Nurse services to allow their skills and expertise to develop:**

    - Educational initiatives to enhance the skills of the generalist practitioners (Practice/District Nurses, GPs etc...) and prevent the unnecessary deterioration of stable patients

    - Promote a palliative care approach when applicable by increasing the holistically supportive pathway for those living with heart failure

- **Ensure that every Specialist Heart Failure Nurse service has access to administration support, provided at an appropriate level to meet their needs and allow them to focus on clinical care and development of the service.**

- **Implement the Healthcare Improvement Scotland 2011 recommendations on the provision of cardiac rehabilitation to focus on those heart failure services which have not previously had access to a cardiac rehabilitation service and increase provision in areas where the current service is inadequate.**

Sources of voluntary support

British Heart Foundation

The British Heart Foundation's (BHF) mission is to play a leading role in the fight against disease of the heart and circulation so that it is no longer a cause of disability and premature death. To help achieve this, the BHF have set a number of objectives across the following areas:

- Research
- Information
- Campaigning
- Care
- Equality.

Since 2002 the BHF have funded and professionally supported Specialist Heart Failure Nurses in the NHS across the UK. In Scotland Specialist Heart Failure Nurses have been funded and continue to be professionally supported by BHF in 15 NHS Health Boards.

Currently a number of posts are being funded for a two year period and are being externally evaluated:

- **IV diuretic community project** – to enable patients with heart failure to have this intervention in their own home. NHS Greater Glasgow & Clyde and NHS Ayrshire and Arran secured funding for a 0.5 WTE Specialist Nurse
- **Healthcare assistant** – to work with an established heart failure team. NHS Western Isles secured funding for 1 post
- **Long Term Condition awards** – 3 NHS trusts have recently secured funding for 2 arrhythmia nurses: 1 in NHS Lanarkshire,1 in NHS Tayside and 1 primary care Heart Failure Nurse in NHS Fife.

The Scottish National Advanced Heart Failure Service (SNAHFS) has recruited a clinical psychologist funded in partnership with BHF. Many patients with heart failure experience emotional distress and behavioural disturbance. It has long been recognised that the psychological care of patients with heart failure is crucial in helping individuals cope with their illness and treatment. The Consultant Clinical Psychologist is based within the SNAHFS at the Golden Jubilee National Hospital on a full-time basis and will be evaluated by the SNAHFS (see Appendix 3 for details of role).

The BHF have and continue to work in partnership with NHS Health Boards and Trusts and other charities on a number of initiatives to improve palliative and supportive care services available to patients with heart failure and their carers. These initiatives include: funding nine palliative care Heart Failure Nurses across the UK for a three year period and collaboration with Marie Curie Cancer Care (MCCC) on three projects: Delivering Choice in Lincolnshire, Better Together in Poole and Bradford and currently Caring Together in Glasgow (see Appendix 4).

Chest Heart & Stroke Scotland

Chest Heart & Stroke Scotland (CHSS) improves the quality of life for people affected by chest, heart and stroke illness, through medical research, influencing public policy, advice and information and support in the community.

CHSS is Scotland's health charity and supports one of the largest charitably funded research programmes in Scotland, with an annual investment of over £600,000. CHSS provides direct support to patients with heart failure and their carers in a number of ways:

- **Heart Failure Support Service:** an innovative model (recommended in Better Heart Disease & Stroke Care Action Plan 2009 and published in the European Journal of Cardiovascular Nursing, Peardon et al 2010), alleviating social isolation, improving quality of life and promoting ability to self-manage;
- **Health Information:** based on current Scottish evidence based guidelines and developed through a system of expert and peer review. CHSS health information is important at every stage of the patient journey, from helping patient and family to come to terms with diagnosis, to supporting them to live with the condition;
- **Advice Line 0845 077 6000:** accredited by the Telephone Helplines Association and providing confidential information and advice from our specialist nurse team on any aspect of heart illness;
- **Affiliated Heart Group network:** peer support and a wide range of activities for people living with cardiac conditions and their families, providing stimulation and companionship in a friendly and relaxed environment within local communities;
- **Voices Scotland programme:** supporting meaningful patient and carer involvement, encouraging people to feel empowered in their own care and in the development of services which support them to live a fulfilled life with their long term condition (recommended as the gold standard of meaningful patient/carer involvement in Managed Clinical Networks: Supporting and Delivering the Healthcare Quality Strategy 2012);
- **Personal Support Grants** (nationally available) **& Benefits Advisors** (available in some areas): for those in financial hardship as a result of their condition.

For more information on all of our services and support, visit www.chss.org.uk or contact the Advice Line on 0845 077 6000 / adviceline@chss.org.uk.

You can also follow us on Facebook: http://www.facebook.com/CHSScotland

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Appendix One

New York Heart Association (NYHA) functional classification system

In order to determine the best course of therapy, the stage of heart failure is assessed according to the New York Heart Association (NYHA) functional classification system.

This system relates symptoms to everyday activities and the patient's quality of life.

NYHA Class	Patient Symptoms
Class I (Mild)	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, or dyspnoea (shortness of breath)
Class II (Mild)	Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitations, or dyspnoea
Class III (Moderate)	Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitations, or dyspnoea
Class IV (Severe)	Unable to carry out any physical activity without discomfort. Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

Appendix Two

NHS QIS 2010
Standard 10: Cardiac rehabilitation

Rationale

Cardiac rehabilitation can significantly reduce morbidity and mortality and improve health-related quality of life.

Essential criteria

10.1 Patients with the following are identified for assessment by the cardiac rehabilitation service:

- acute coronary syndrome
- coronary by-pass surgery (elective and urgent)
- percutaneous coronary intervention (elective and urgent)
- patients attending chest pain assessment services with new onset or worsening angina
- heart valve surgery
- heart transplant
- implantable cardioverter defibrillator
- chronic stable heart failure.

10.2 Patients identified are assessed by the cardiac rehabilitation team for a menu-based programme as specified in current national guidelines.

10.3 Assessed patients are offered a menu-based programme according to their needs

Healthcare Improvement Scotland 2011
Heart Disease Improvement Programme - 4 point assessment scale

Level 1: The NHS board is **Developing** its policies, strategies, systems and processes to deliver heart disease services in line with national evidence, standards and guidance;

Level 2: The NHS board is **Implementing** its policies, strategies, systems and processes to deliver care in line with national evidence, standards and guidance;

Level 3: The NHS board is **Monitoring** the effectiveness of its policies, strategies, systems and processes to deliver care in line with national evidence, standards and guidance;

Level 4: The NHS board is **Reviewing** and continuously improving its policies, strategies, systems and processes to deliver care in line with national evidence, standards and guidance.

Appendix Three

Consultant in Psychocardiology
Scottish National Advanced Heart Failure Service

Clinical health psychologists use in-depth and up-to-date knowledge of research evidence to improve health outcomes and maximise health gains. Many patients seen by psychologists are distressed as a result of their heart failure or the associated medical treatments or surgical interventions. Some have co-morbid mental health and physical health problems. Clinical health psychologists are competent in assessing the influence of mental health problems on physical welfare and helping patients effectively manage their physical condition.

The role includes:

- assessment of emotional and behavioural well-being at pre-, peri- and post-transplant stages
- helping patients come to terms with or adjust to their illness and treatment
- improving the uptake of medical treatment and adherence to complex treatment regimens
- helping to reduce psychological distress where this is interfering with treatment and recovery
- ensuring patients have capacity to consent to interventions
- assisting patients and health care professionals in decision-making about treatment
- assisting patients to make lifestyle changes that maintain and improve health.

The psychologist has a long-standing interest in heart failure and is keen to promote the integration of psychological care within the routine clinical practice of heart failure healthcare professionals.

In addition to providing direct assessment and therapeutic work with individuals and their families, the role also involves implementing teaching and training in the application of psychological skills to Specialist Heart Failure Nurses across Scotland to improve the health and well-being of patients with advanced heart failure and being active in research and evaluation of innovative approaches to patient care.

Appendix Four

'Caring Together'
British Heart Foundation / Marie Curie Cancer Care

This five-year programme aims to improve the quality of and access to palliative care for patients in the advanced stages of heart failure in NHS Greater Glasgow & Clyde
Caring Together is developing pioneering models of palliative care for patients in the advanced stages of heart failure which support the delivery of palliative care for these patients in all care settings – hospital, hospice, care home and at home. The integrated models meet the needs of patients and their carers, while complementing the optimal management of heart failure (and other diagnosed conditions). The models promote equity of access to palliative care for patients with heart failure, increase their choice in place of care and improve communication and coordination of care between all healthcare professionals involved in their care.

Patients have benefited from improved access to palliative care services in hospital, hospices, at home and in care homes. With better coordination and provision of care, patients have been provided with choice in their place of care. There has been increased support provided to families and carers including information about heart failure and how it affects the patient, and how they can get help when needed or referral to other services.

A training needs analysis has been undertaken to determine the training needs of clinicians and a number of research and evaluation activities are associated with the programme.

Appendix Five

SHFNF Review Data 2012

NHS Board	AA	BO	DG	FI	FV	GR	GGC
Service commenced	May 2004	April 2007	April 2002	Aug 2004	Dec 1999	Mar 2004	Aug 1999
Board population	366,860	112,870	148,190	364,945	293,386	550,620	1,203,870
Urban profile %	78	47	46	79	80	64	98
Rural profile %	22	53	54	21	20	36	2
WTE posts 2012	4	1.3	2	2	3	2.65	14.62
Actual staff 2012	7	3	2	2	4	4	17
WTE posts 2008	5	2.5	2	2	3.2	2	16.3
SIGN Ratio 2012	1: 91,715	1: 86,823	1: 74,095	1: 182,473	1: 97,795	1: 207,781	1: 82,344
SIGN Ratio 2008	1: 73,290	1: 44,499	1: 74,015	1: 179,429	1: 89,392	1: 264,944	1: 73,103
WTE Caseload 2012	125	80	75	70	140	100	100
WTE Caseload 2008	90	36	50	70	140	0	100
Total pts 1 year	348	140	268	238	300	250	1,300
Home/clinic model	80% / 20%	75% / 25%	38% / 62%	80% / 20%	20% / 80%	80% / 20%	35% / 65%
Provision for HF-PEF	No	No	No	Yes	No	No	No
Admin supp. hrs/pw	18.75	15	20	9	30	3	129.75
Education provision	Yes	Limited	Yes	Yes	Yes	Limited	Yes
Specialist support	1(non-sp)	None	None	Yes	Yes	None	5
CR available	Yes	No	Yes	Limited	Yes	No	No
CR no. seen pa	80	0	53	Unknown	50	0	0
Psych. Support	Recruiting	Inad.	Inad.	Inad.	Ad.	None	None

NHS Board	HI	LA	LO	OR	SH	TA	WI
Service commenced	Nov 2006	Oct 2004	Mar 2002	Mar 2007	Jun 2005	May 2004	Apr 2007
Board population	310,830	562,477	836,711	20,110	22,400	402,641	26,190
Urban profile %	31	89	89	0	0	77	0
Rural profile %	69	11	11	100	100	24	100
WTE posts 2012	4.5	3.6	4	0	0.5	3	2
Actual staff 2012	8	4	4	0	1	3	3
WTE posts 2008	3.4	3	5	1	0.3	3	2
SIGN Ratio 2012	1: 69,073	1: 156,244	1: 209,178	N/A	1: 44,800	1: 134,214	1: 13,095
SIGN Ratio 2008	1: 78,385	1: 186,046	1: 200,328	1: 19,770	1: 72,390	1: 130,546	1: 13,075
WTE Caseload 2012	60	100	90	0	100	90	120
WTE Caseload 2008	60	100	100	35	15	80	35
Total pts 1 year	289	400	310	0	120	515	240
Home/clinic model	70% / 30%	80% / 20%	40% / 60%	N/A	40% / 60%	70% / 30%	30% / 70%
Provision for HF-PEF	No	No	No	No	No	No	No
Admin supp. hrs/pw	31	13	16-20	10	0	30	22.5
Education provision	Yes	No	Yes	Limited	Yes	Yes	No
Specialist support	2	2	None	None	1(non-sp)	2	1 GPwSI
CR available	Limited	Limited	Yes	Yes	Yes	Yes	Yes
CR no. seen pa	Unknown	3	Unknown	Unknown	20	25	20
Psych. Support	No	None	Ad.	Ad.	None	None	None

Scottish Heart Failure

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2013