

# Patients with heart failure are not receiving cardiac rehabilitation: a cross-sectional study of common barriers

Journal:	BMJ Open
Manuscript ID:	bmjopen-2011-000787
Article Type:	Research
Date Submitted by the Author:	04-Jan-2012
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 b>Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Cardiovascular medicine
Keywords:	Adult cardiology < CARDIOLOGY, Heart failure < CARDIOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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# Patients with heart failure are not receiving cardiac rehabilitation: a cross-sectional study of common barriers

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Abstract: 255 words; Main text: 3008 words;

Number of figures: 1; Number of tables: 3

Supplementary files: 2 survey questionnaires

#### **Summary**

Article focus

To determine why so few patients with chronic heart failure in England, Wales, and Northern Ireland take part in cardiac rehabilitation

To find out the features of cardiac rehabilitation centres that offer a service to patients with heart failure

Key messages

Most cardiac rehabilitation centres in England, Wales, and Northern Ireland do not routinely offer cardiac rehabilitation to people with chronic heart failure

- Only one in six cardiac rehabilitation centres offers a dedicated cardiac
  rehabilitation programme for patients with heart failure. Those with heart failure (New
  York Heart Association (NYHA) stages I to III) after myocardial infarction or coronary
  revascularisation have the best chance of getting on a cardiac
  rehabilitation programme
- Lack of resources and exclusion from local commissioning agreements are seen as the main reasons for not offering cardiac rehabilitation to people with heart failure

Strenghts and limitations

The first comprehensive national survey of cardiac rehabilitation services for patients ιe Of (

can be drawn from stage 2 t

rate. with heart failure with a respose rate 0f 84% conducted with the National Audit of Cardiac Rehabilitation (NACR).

The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate.

#### Abstract

**Objectives** To determine why so few patients with chronic heart failure in England, Wales, and Northern Ireland take part in cardiac rehabilitation.

**Design** Two-stage, postal questionnaire-based, national survey.

Participants and setting Stage 1: 277 cardiac rehabilitation centres that provided phase III cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register. Stage 2: 35 centres that indicated in stage 1 that they provide a separate cardiac rehabilitation programme for patients with heart failure.

Results Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure, 84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. No difference was seen in the skill mix between programmes that did or did not provide rehabilitation for patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

**Conclusion** Patients with heart failure as a primary diagnosis are excluded from most cardiac rehabilitation programmes in England, Wales, and Northern Ireland. A lack of resources and direct exclusion from local commissioning agreements are the main barriers for not offering rehabilitation to patients with heart failure.

#### What is already known on this topic

- In the UK nearly a million people are living with chronic heart failure but only a very small minority have participated in cardiac rehabilitation
- Recent systematic reviews of exercise based cardiac rehabilitation have found significant improvements in health related quality of life and reductions in hospitalisation in patients with systolic heart failure following cardiac rehabilitation compared with usual care
- Several international guidelines, including the current guidance from the National Institute for Health and Clinical Excellence (NICE), recommend cardiac rehabilitation in chronic heart failure

#### What this study adds

- Most cardiac rehabilitation centres in England, Wales, and Northern Ireland do not routinely offer cardiac rehabilitation to people with chronic heart failure
- Only one in six cardiac rehabilitation centres offers a dedicated cardiac
  rehabilitation programme for patients with heart failure. Those with heart failure
  (New York Heart Association (NYHA) stages I to III) after myocardial infarction or
  coronary revascularisation have the best chance of getting on a cardiac
  rehabilitation programme
- Lack of resources and exclusion from local commissioning agreements are seen as the main reasons for not offering cardiac rehabilitation to people with heart failure

#### Introduction

Heart failure is becoming more prevalent worldwide,<sup>1</sup> mainly due to ageing of the population and improved survival after acute cardiac events. In the UK, about 900,000 people are living with heart failure.<sup>2</sup> Numerous national and international evidence-based guidelines have been developed to improve diagnosis and treatment for patients with heart failure and have covered aetiology, prevention, diagnosis, and therapeutic interventions.<sup>3-5</sup> Exercise training has been evaluated intensively with respect to the benefit that it may provide in the treatment of those with heart failure.<sup>6</sup> Strong evidence from meta-analyses shows that cardiac rehabilitation improves quality of life, reduces symptom burden, and reduces readmissions to hospital in patients with systolic heart failure.<sup>7</sup>

Current guidelines from the National Institute for Health and Clinical Excellence (NICE), American College of Cardiology (ACC)/American Heart Association (AHA), and European Society of Cardiology (ESC) recommend cardiac rehabilitation as an effective and safe intervention for heart failure. 8-10,20 These guidelines all recommend that cardiac rehabilitation programmes should not be restricted to exercise alone but should include education, psychological input, and drug therapy; in other words, comprehensive cardiac rehabilitation to enhance self management and help patients achieve better long-term management of their chronic illness.

Despite the clear recommendations in the various guidelines, only a small minority of people affected by heart failure in the UK, and elsewhere, have participated in cardiac rehabilitation. <sup>11,12</sup> In the UK between April 2007 and March 2008, only 1% of patients who participated in cardiac rehabilitation were referred because of heart

failure,<sup>11</sup> and a recent European survey showed that <20% of patients with heart failure are involved in cardiac rehabilitation.<sup>12</sup> Two main reasons may explain the suboptimal provision and uptake of this intervention in people with cardiac rehabilitation: the guidelines provide no specific details for healthcare planners about how and where these cardiac rehabilitation services would best be delivered, and healthcare staff involved in frontline cardiac rehabilitation services are unsure about the safety and benefits of cardiac rehabilitation in people with heart failure.<sup>13</sup>

Most trials of cardiac rehabilitation have excluded patients with heart failure and preserved ejection fraction (diastolic heart failure), who make up 54% of the population with heart failure, and it is not clear to what extent they are specifically excluded from cardiac rehabilitation in routine practice. <sup>14</sup> In the UK, an emphasis has been placed on providing choice between hospital based rehabilitation and home based individual programmes such as the Heart Manual <sup>15</sup> after myocardial infarction, as such a choice has been shown to increase uptake. <sup>16</sup>

We conducted a two-stage national survey in 2009-10. This study aimed firstly to ascertain why such a small percentage of people with heart failure are receiving cardiac rehabilitation given that it is so widely acknowledged as beneficial and secondly to find out more about those centres that are providing a service specifically for heart failure. We therefore assessed current provision of cardiac rehabilitation for patients with heart failure in England, Wales, and Northern Ireland (stage 1) and obtained data on the features of cardiac rehabilitation centres that did offer cardiac rehabilitation for patients with heart failure (stage 2).

#### Methods

#### Stage 1

Stage 1 of the national survey included all centres that provided phase III rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation (NACR) database funded by the British Heart Foundation. Each centre was sent a 17 item, one page postal questionnaire that asked respondents to indicate whether they routinely provided a cardiac rehabilitation service for patients with heart failure and to identify and give brief details about barriers to provision of such a service. The stage 1 questionnaire was mailed out by the NACR office in York (see eBMJ for the stage 1 questionnaire). To validate the data, responses from stage 1 in terms of the demographic and activity features of the centres were compared with information from the NACR (the methods and measures used by the NACR are described on and available for download from www.cardiacrehabilitation.org.uk/nacr).

#### Stage 2

Stage 2 of the survey was sent from the Royal Cornwall Hospitals Trust and included all centres that confirmed in stage 1 that they provided a separate cardiac rehabilitation service for patients with heart failure. These centres were sent a 44 item, five page questionnaire designed to find out more about the nature (patient demographics and staffing) and content of their cardiac rehabilitation service (see eBMJ for the stage 2 questionnaire). In the first instance, the stage 2 questionnaire was sent by email, with a letter explaining why more detailed information was being requested from the centres. To optimise response rates, non-responders were sent personalised letters with stamped addressed envelopes, and these were followed by

reminder emails and telephone calls.

#### Data analysis

We entered participating centres' responses into an Excel spreadsheet. We undertook frequency analyses for stages 1 and 2. We compared the results of the stage 1 questionnaire between centres that did provide separate cardiac rehabilitation programmes for HF and those that did not. We made comparisons using the  $\chi^2$  test for binary data and Mann-Whitney U tests for ordinal data. We analysed data with SPSS software (version 19).

#### Results

#### Stage 1

Of the 277 questionnaires sent out to cardiac rehabilitation centres in England, Wales, and Northern Ireland, 232 (84%) were completed and returned (figure 1). Eight (3.4%) of these 232 centres did not respond to the first question: 'Do you routinely offer phase III cardiac rehabilitation to people with heart failure?', which meant that 224 (81%) responses were eligible for full analysis. Table 1 summarises the response to the key questions in stage 1.

<< Figure 1 near here>>

<<Table 1 near here>>

Of the 224 centres with complete responses, 134 (60%) reported that they did not routinely accept people with heart failure and 90 (40%) that they did routinely offer phase 3 cardiac rehabilitation in heart failure. Of the 90 centres that did offer cardiac

rehabilitation in heart failure, 39 (43%) did so only when heart failure was secondary to referral after myocardial infarction or revascularisation. Overall, only 35/224 (16%) responding centres specifically recruited patients with heart failure. Only 33/90 (37%) centres responded to a question asking about their provision of cardiac rehabilitation for patients with heart failure with preserved ejection fraction (diastolic heart failure), with only one third (11/33) taking patients from this group. Patients with heart failure and preserved ejection fraction were included in cardiac rehabilitation programmes by 11/90 (12%) centres, with 79 centres accepting only patients with systolic heart failure. Patients with New York Heart Association (NYHA) class IV disease were excluded by 53/90 (59%) centres.

Of the 90 centres that did offer cardiac rehabilitation for heart failure, 35 (39%) had a specific cardiac rehabilitation programme for this patient group. Of these, 27 (30%) offered a home based cardiac rehabilitation programme such as the Heart Manual or the British Heart Foundation's Heart Failure Plan. Hospital-based rehabilitation for groups was offered in 72 (80%) centres, with only 30 (33%) offering a choice between home based and centre based programmes.

From the 134 centres that did not routinely offer rehabilitation in heart failure 113 (84%) indicated that a lack of resources was a factor and 73 (54%) indicated that the exclusion of such a service from commissioning contracts had influenced decisions on its provision. More than half (54%) of the centres expressed confidence in the skill mix and knowledge of their staff to provide cardiac rehabilitation in heart failure.

Table 2 summarises the reasons given by the 90 cardiac rehabilitation centres that stated they did not offer cardiac rehabilitation for heart failure. Importantly, overall

146/224 (65%) centres considered that evidence on safety was adequate and 159/224 (71%) did not believe lack of evidence on clinical benefit was an influencing factor.

<<Table 2 near here>>

Comparison between centres that did and did not provide CR in HF

A higher percentage of patients diagnosed with heart failure were referred to centres that offered cardiac rehabilitation in heart failure (4.6%) than to those that did not (0.6%) (P<0.05). A statistically significant difference was also seen in the median number of patients referred per annum between the centres that routinely offered cardiac rehabilitation in heart failure and those that did not (287 versus 202, respectively; P=0.03). Nearly three out of four patients seen were men: 73% in centres offering and 74% in those not offering cardiac rehabilitation in heart failure. Patients who survived myocardial infarction (32%) and coronary artery bypass surgery (19%) formed the largest proportion of patients with heart failure receiving cardiac rehabilitation. The skill mix did not differ significantly between programmes that did (n=90) or did not (n=134) offer cardiac rehabilitation (Table 3).

<<Table 3 near here>>

#### Stage 2

Only 35 (16%) of the 224 respondents in stage 1 had indicated that they provided a separate cardiac rehabilitation programme for people with heart failure. Of these 35 centres, 24 (69%) agreed to provide more information about their heart failure

service and were willing to participate in stage 2 of the survey. Complete stage 2 questionnaires were received from 17 (71%) of these 24 centres.

The geographical area of responding centres was mainly urban (10/17; 59%) or mixed rural and urban (7/17; 41%). The number of patients with heart failure seen annually varied widely, with 5/17 (29%) centres seeing 10–50 referred patients, 4/17 (24%) centres seeing 51–100 patients, and 3/17 (18%) seeing more than 100 patients.

Centres with dedicated cardiac rehabilitation services for heart failure were based mainly in district general hospitals (6/17; 35%) or the community (5/17; 29%) or had clinics in both settings (4/17; 24%). A combination of hospital based and home based programmes was offered by 41% of centres, with 47% offering only hospital based programmes. Seven centres offered both centre based and home based cardiac rehabilitation, and nearly half (8/17) offered only a centre based cardiac rehabilitation programme. The duration of the cardiac rehabilitation programmes offered was <6 weeks for 12% of centres, 6–12 weeks for 59%, and >12 weeks for 24%. A home exercise programme was offered in 10 centres.

Supervised exercise training was a key component of almost all (95%) of the dedicated cardiac rehabilitation for heart failure programmes, with 11/17 (65%) centres including sessions lasting up to one hour and 5/17 (29%) including sessions of up to two hours. All centres provided education on heart failure, self management, medication, and diet.

Anxiety and depression were assessed by more than 80% (14/17) of centres, with 71% using the hospital anxiety and depression scale (HADS) questionnaire. More than half of centres referred patients with high levels of anxiety and depression to their general practitioner or counsellor.

Centres that offered a dedicated rehabilitation programme in heart failure employed 3–4 whole time equivalent members of staff (7/17), with most employing cardiac rehabilitation nurses, physiotherapists, heart failure specialist nurses, and a coordinator. Few centres reported employing a psychologist (2/17) or dietician (3/17) as a member of their cardiac rehabilitation teams.

#### **Discussion**

Our survey shows that 60% of the cardiac rehabilitation centres in England, Wales, and Northern Ireland did not accept patients with heart failure, although most of those completing the survey accepted that there was good scientific evidence of benefit. This is not a new concern. The Healthcare Commission reported in 2007 that only 5.7% of 6 998 patients with heart failure surveyed were referred for cardiac rehabilitation. A 2008 national audit of cardiac rehabilitation in the UK reported that the cardiac rehabilitation service for heart failure was patchy or non-existent in many areas, and the 2010 NACR report states that 60 477 patients participated in cardiac rehabilitation although one in four cardiac rehabilitation centres excluded patients with heart failure and only 1% of participants were referred because of heart failure. The Healthcare Commission also reviewed progress on the implementation of the national service framework for coronary heart disease and highlighted the need to improve access and provision of cardiac rehabilitation services for people

with heart failure. 13,18 This implementation gap has also been reiterated by the NHS Institute for Innovation and Improvement. 19 Most cardiac rehabilitation centres are not implementing the latest guidance from NICE. 20

Our survey aimed to discover why there is a problem with delivery. Most programme coordinators regarded the major barriers to providing a service for heart failure as local commissioning arrangements, local patient pathways, other people (for example, heart failure specialist nurses) providing a similar service, or lack of resources. Only a very small number expressed doubt about safety, their competency, or the skill mix. A significant difference was identified in the annual number of patients seen in those centres that did and did not have a dedicated heart failure programme, with larger programmes more likely to have such a programme. However, taken as a whole, no difference was seen in the staff mix of programmes that did or did not specifically recruit patients with heart failure. This suggests that most existing cardiac rehabilitation centres could provide such a service if commissioners were to include heart failure in the contract and only a few would require some further education or expertise.

In the 134/224 (60%) centres that did not routinely offer cardiac rehabilitation in heart failure in the UK, the main barriers were lack of resources and lack of commissioning. Nearly one third (29/90) of centres that provided cardiac rehabilitation in heart failure did not consider a lack of resources—time, staff, accommodation, transport, or equipment—as an issue. Most (67/90) centres that provided cardiac rehabilitation indicated that they had the correct skill mix and knowledge to manage patients with heart failure. In contrast to the findings of the

Healthcare Commission, which reported that frontline cardiac rehabilitation services are unsure about the safety and benefits of rehabilitation in heart failure, <sup>13</sup> our survey found that a lack of evidence on safety or clinical benefit was not a factor that influenced most centres' ability to offer cardiac rehabilitation.

Overall, a dedicated cardiac rehabilitation service for heart failure was reported by only 35/224 (16%) centres, with 90/224 (40%) offering cardiac rehabilitation to some patients with heart failure. Of these, a mere 11/90 (12%) provided any support for the 54% of the heart failure population with heart failure and preserved ejection fraction. The latter presents a similar burden to systolic heart failure in terms of healthcare costs, rehospitalisation rates, mortality, exercise intolerance, and quality of life. Odd evidence supports the benefits of cardiac rehabilitation in systolic heart failure in terms of quality of life, exercise capacity, and reduced rates of hospital readmission related to heart failure. The same cannot be said for heart failure with preserved ejection fraction, however, for which evidence is limited; research is therefore needed to assess definitively the effectiveness and cost effectiveness of exercise based cardiac rehabilitation interventions.

Patients with less severe forms of systolic heart failure (NYHA class I–III) after a heart attack or coronary revascularisation have the best chance of being offered cardiac rehabilitation. One third (27/90) of cardiac rehabilitation centres offering services to patients with heart failure offered a home-based programme, and a similar proportion (30/90) offered a choice of home or centre based cardiac rehabilitation. The lack of an alternative evidence based intervention to centre based cardiac rehabilitation and the lack of referral by healthcare professionals may explain

why uptake of cardiac rehabilitation remains suboptimal in patients with heart failure.

The main reasons people give for not accepting an invitation to attend centre based cardiac rehabilitation classes are problems with accessibility and parking at their local hospital, a dislike of groups, and work or domestic commitments. <sup>25–29</sup> These problems might be overcome by home based programmes, which have been introduced in an attempt to widen access and participation. Evidence on the effectiveness of home based models of cardiac rehabilitation in people with heart failure is needed so that policymakers and commissioners can decide what to provide as part of a comprehensive cardiac rehabilitation service for people with heart disease. A trial based in the United Kingdom of home exercise compared with care by a specialist heart failure nurse, without other educational elements, in patients with stable heart failure on optimised therapy failed to find a benefit in heart failure specific quality of life. <sup>30</sup> However, adherence to the programme was relatively low, with participants having a large number of comorbid conditions that may have required more specialist exercise input rather than a nurse led service.

Choice in healthcare is a government priority.<sup>31</sup> One recent randomised controlled trial of cardiac rehabilitation in a rural setting used a comprehensive cohort design that allowed participants a choice of centre based or home based cardiac rehabilitation.<sup>32,33</sup> The Cornwall Heart Attack Rehabilitation Management Study (CHARMS) investigators showed that most recruited patients (55%) wanted to choose their method of cardiac rehabilitation and that outcomes did not differ between the randomised and preference arms.<sup>33</sup>

In October 2011, NICE published updated guidance on commissioning cardiac rehabilitation services to accompany the recommendations within the NICE clinical guideline on chronic heart failure.<sup>20</sup> The advice will be linked to the outcomes and indicators specified in the NHS outcomes framework and should help 'commissioners in designing services to improve outcomes for patients and to help the NHS make better use of its resources'.<sup>34</sup>

#### Limitations of the study

The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate (n=17). Although we obtained detailed information about centres that provided a separate cardiac rehabilitation programme for patients with heart failure, inferences from this part of the study should be treated with caution.

#### Recommendations from this study

Commissioning groups should follow the recently developed NHS Commission's guide to coronary heart disease and the need for cardiac rehabilitation<sup>35</sup> and the recently published NICE guidance on commissioning on cardiac rehabilitation<sup>34</sup> for all newly diagnosed patients with chronic heart failure. Part of this guidance recommends offering all patients a choice of venue (home or hospital) for cardiac rehabilitation, although there is little evidence on the effectiveness of home based models of cardiac rehabilitation in people with heart failure, including programmes that may be suitable for patients with heart failure and preserved ejection fraction—robust evidence for these is needed.

#### **Footnotes**

The authors thank Jemma Lough for her assistance in editing the manuscript, Tony Mourant for comments on earlier drafts of the manuscript, and Christopher Hocking for help with the literature search.

Contributors: RL and RST conceived the original idea of conducting the survey. HD, RST, RL, and JP wrote the paper. The survey questionnaires were designed by the REACH-HF Study Group and administered by CP via the National Audit of Cardiac Rehabilitation office in York and by JW and HD in Truro. CP and JP were involved in collating the data and data input. JP and RT analysed the data. HD and RL are joint guarantors for this study. The REACH-HF investigators include the authors HD, RL, RST, and JW, as well as Patrick Doherty, Kate Jolly, Russell Davis, Sally Singh, Jackie Austin, Robert Williams, Colin Green, Colin Greaves, Robin van Lingen, Lorna Geach and John Packard.

Funding: This study was supported by a Programme Development Grant (RP-DG-0709-10111) from the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors and not necessarily those of the NHS, NIHR, or Department of Health.

Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org/coi\_disclosure.pdf (available on request from the corresponding author) and declare that (1) none have support from commercial companies for the submitted work; (2) none have relationships with commercial companies that might have an interest in the submitted work in the previous three years; (3) their spouses,

partners, or children have no financial relationships that may be relevant to the submitted work; and (4) none have non-financial interests that may be relevant to the submitted work.

Ethical approval: Not required

#### References

- Adams KF. Translating heart failure guidelines into clinical practice: clinical science and the art of medicine. Curr Cardiol Rep 2001;3(2):130–5.
- 2. Bethell HJ, Evans JA, Turner SC, et al. The rise and fall of cardiac rehabilitation in the United Kingdom since 1998. *J Public Health (Oxf)* 2007;**29**(1):57–61.
- 3. Hunt SA, Baker DW, Chin MH, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: executive summary a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Committee to Revise the 1995 Guidelines for the Evaluation and Management of Heart Failure): developed in collaboration with the International Society for Heart and Lung Transplantation; endorsed by the Heart Failure Society of America. Circulation 2001;104(24):2996–3007.
- 4. Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *Eur Heart J* 2001;**22**(17):1527–60.
- 5. Task Force on Heart Failure of the European Society of Cardiology. Guidelines for the diagnosis of heart failure. *Eur Heart J* 1995;**16**(6):741–51.
- European Heart Failure Training Group. Experience from controlled trials of physical training in chronic heart failure. Protocol and patient factors in effectiveness in the improvement in exercise tolerance. *Eur Heart J* 1998;19:466–75.
- 7. Davies EJ, Rees K, Moxham T, et al. Exercise based rehabilitation for heart failure. *Eur J Heart Fail* 12.7 (2010): 706-15

- 8. NICE. Chronic heart failure. National clinical guidelines for diagnosis and management in primary and secondary care. National guideline No 5. London: Royal College of Physicians, 2003.
- 9. Hunt SA, Abraham WT, Chin MH, et al. 2009 focused update incorporated Into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines developed in collaboration with the International Society for Heart and Lung Transplantation. Circulation 2009;119(14):e391–479.
- 10. Dickstein K, Cohen-Solal A, Filippatos G, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). Eur Heart J 2008;29:2388–442.
- British Heart Foundation Cardiac Care and Education Research Group. The National Audit of Cardiac Rehabilitation. Annual statistical report 2009. BHF: London, 2009.
   Available at: www.cardiacrehabilitation.org.uk/nacr/docs/2009.pdf (last accessed 12 November 2009).
- Bjarnason-Wehrens B, McGee H, Zwisler AD, et al. Cardiac rehabilitation in Europe: results from the European Cardiac Rehabilitation Inventory Survey. Eur J Cardiovasc Prev Rehabil 2010;17(4):410–8.
- Healthcare Commission. *Pushing the boundaries*. London: Healthcare Commission, 2007.
- 14. Lam CS, Donal E, Kraigher-Krainer E, et al. Epidemiology and clinical course of heart failure with preserved ejection fraction. *Eur J Heart Fail* 2011;13:18-28.
- Lewin B. Effects of self-help post-myocardial-infarction rehabilitation on psychological adjustment and use of health services. *Lancet* 1992;339:1036-40.

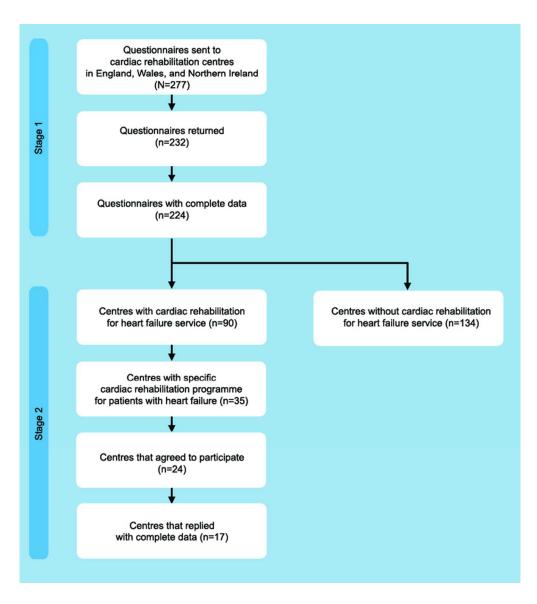
- Dalal HM, Evans PH. Achieving national service framework standards for cardiac rehabilitation and secondary prevention. *BMJ* 2003;326:481-4.
- 17. British Heart Foundation Cardiac Care and Education Research Group. *National audit of cardiac rehabilitation. Annual statistical report 2010.* London: BHF, 2010.
- 18. Department of Health. Coronary heart disease: national service framework for coronary heart disease. London: DH, 2000.
- 19. NHS Institute for Innovation and Improvement. *Delivering quality and value. Focus on:*heart failure. Coventry: NHS Institute for Innovation and Improvement, 2009. Available at: www.institute.nhs.uk (last accessed 11 November 2009).
- 20. NICE. Chronic Heart Failure. Management of chronic heart failure in adults in primary and secondary care. NICE clinical guideline CG108. London: NICE, 2010. Available at: http://guidance.nice.org.uk/nicemedia/live/13099/50514/50514.pdf (last accessed 2 September 2011).
- 21. Owan TE, Redfield MM. Epidemiology of diastolic heart failure. *Prog Cardiovasc Dis* 2005;47: 320-32.
- 22. Liao L, Anstrom KJ, Gottdiener JS, et al. Long-term costs and resource use in elderly participants with congestive heart failure in the Cardiovascular Health Study. *Am Heart J* 2007;153:245-52.
- Kitzman DW, Little WC, Brubaker PH, et al. Pathophysiological characterization of isolated diastolic heart failure in comparison to systolic heart failure. *JAMA* 2002;288:2144-50.
- Gottdiener JS, McClelland RL, Marshall R, et al. Outcome of congestive heart failure in elderly persons: influence of left ventricular systolic function. The Cardiovascular Health Study. *Ann Intern Med* 2002;137:631-9.
- 25. Jones M, Jolly K, Raftery J, et al. 'DNA' may not mean 'did not participate': a qualitative study of reasons for non-adherence at home and centre-based cardiac rehabilitation.
  Fam Pract 2007;24(4):343–57.

- 26. Ades PA, Waldmann ML, McCann WJ, et al. Predictors of cardiac rehabilitation participation in older coronary patients. *Arch Intern Med* 1992;**152**(5):1033–5.
- 27. Ferguson EE. Cardiac rehabilitation an effective and comprehensive but underutilized program to reduce cardiovascular risk in patients with CVD. *US Cardiovasc Dis* 2006;**II**:14–6.
- 28. Campbell N, Grimshaw J, Rawles J, et al. Cardiac rehabilitation: the agenda set by post-myocardial infarction patients. *Health Educ J* 1994;**53**:409–20.
- 29. Pell J, Pell A, Morrison C, et al. Retrospective study of influence of deprivation on uptake of cardiac rehabilitation. *BMJ* 1996;**313**:267–8.
- 30. Jolly K, Taylor RS, Lip GY, et al. A randomized trial of the addition of home-based exercise to specialist heart failure nurse care: the Birmingham Rehabilitation Uptake Maximisation study for patients with Congestive Heart Failure (BRUM-CHF) study. Eur J Heart Fail 2009;11(2):205–13.
- 31. Lewis RQ. A new direction for NHS community services. BMJ 2006;332(7537):315.
- 32. Wingham J, Dalal HM, Sweeney KG, et al. Listening to patients: choice in cardiac rehabilitation. *Eur J Cardiovasc Nurs* 2006;5:289-94.
- 33. Dalal HM, Evans PH, Campbell JL, et al. Home-based versus hospital-based rehabilitation after myocardial infarction: a randomized trial with preference arms – Cornwall Heart Attack Rehabilitation Management Study (CHARMS). *Int J Cardiol* 2007;119(2):202–11.
- 34. National Institute for Health and Clinical Excellence. Advice from NICE aims to improve commissioning of services for people with chronic heart failure and for people who need cardiac rehabilitation. London: NICE, 2011. Available at:

  www.nice.org.uk/newsroom/pressreleases/chronicheartfailurecardiacrehabilitationcommi ssioningguides.jsp (last accessed 23 November 2011).
- 35. Department of Health. Commissioning a cardiac rehabilitation service: reabling people with coronary heart disease. London: DH, 2010. Available at:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH 117504 (last accessed 23 November 2011).





Study flow chart 290x324mm (72 x 72 DPI)

**Table 1** Summary of responses to the key questions in stage 1.

Question	N	o (%) respo	nse
	Yes	No	Missing
Do you routinely offer phase III cardiac rehabilitation to people with	90	134	NA
heart failure? (n=224)	(40.1)	(59.9)	
Which of these best describes the heart failure pathway into cardiac			
rehabilitation in your area?			
Usually only if they have been referred for acute myocardial	39	12	39 (43.4)
infarction or revascularisation (n=90)	(43.3)	(13.3)	
We offer cardiac rehabilitation to all people with heart failure	56	17	17 (18.9)
regardless of the cause (n=90)	(62.2)	(18.9)	
We don't usually take people with diastolic heart failure (n=90)	11	22	57 (63.3)
	(12.2)	(24.4)	
Do you provide a separate programme for heart failure patients?	35	52	3 (3.3)
(n=90)	(38.9)	(57.8)	
If yes, are spouses/partners invited to participate in cardiac	37	29 (32.2)	24 (26.7)
rehabilitation? (n=90)	(41.1)		
Do you provide a home based cardiac rehabilitation programme for	27	56	7 (7.8)
heart failure? (n=90)	(30.0)	(62.2)	
Do you provide a hospital/centre based programme for patients with	72	15 (16.7)	3 (3.3)
heart failure? (n=90)	(80.0)		
Do you offer heart failure patients a choice of home or centre based	30	56 (62.2)	4 (4.4)
cardiac rehabilitation? (n=90)	(33.3)		
Do you offer cardiac rehabilitation to New York Heart Association	16	56 (62.2)	18 (20.0)
class IV patients? (n=90)	(17.8)		
Do any of the following factors influence you in offering/not offering			
cardiac rehabilitation to people with heart failure?			
Not enough resources (n=90)	29	50	11 (12.2)
	(32.2)	(55.6)	
HF patients are not included in our contract with the	16	54 (60.0)	20 (22.2)
commissioners (n=90)	(17.8)		
We are not confident that we have the right skill mix/knowledge	8 (8.9)	67 (74.4)	15 (16.7)
to manage these patients (n=90)			
Lack of evidence/guidance on safety (n=90)	6 (6.7)	71 (78.9)	13 (14.4)
Lack of evidence on clinical benefit (n=90)	2 (2.6)	74	14 (15.6)
		(82.2)	

NA=not applicable.

**Table 2** Reasons cardiac rehabilitation programmes give for not offering cardiac rehabilitation for patients with heart failure.

Reason cited	No (%) of centres
Lack of resources	29 (32)
No contract for heart failure	16 (18)
Heart failure specialist nurse already meets cardiac rehabilitation need	14 (16)
Lack of referrals from heart failure service clinicians	11 (12)
Patients go to another cardiac rehabilitation programme in area	9 (10)
Not confident in having the correct skill mix	8 (9)



**Table 3** Staffing mix in centres that did (n=90) and did not (n=134) offer cardiac rehabilitation for heart failure.

Discipline	Number (%) of centres		P value
	Offering cardiac	Not offering cardiac	
	rehabilitation for	rehabilitation for	
	heart failure	heart failure	
	(n=90)	(n=134)	
Consultant/doctor	7 (7.8)	10 (7.5)	0.186
Physiotherapist/exercise specialist	39 (43.3)	49 (36.6)	0.210
Physiotherapy assistant	15 (16.7)	25 (18.7)	0.736
Dietician	46 (51.1)	70 (52.2)	0.538
Psychologist	9 (10)	13 (9.7)	0.122
Secretary/administrator	56 (62.2)	81 (60.4)	0.700
Healthcare assistant	5 (5.6)	13 (9.7)	0.587

## **Cardiac Rehabilitation for People with Heart Failure**

1	Do you routinely offer Yes ☐ Go to Q2 Phase III cardiac	13	Is inclusion based on LV ejection fraction?	Yes No	_
	rehabilitation to people No Go to Q14 with heart failure?		If yes, please give %:		<b>-</b>
2	Please tick which Phases you	14	Do you have any other exclusion criteria?  If yes,	Yes No	_
3	Which of these best describes the HF pathway into CR in your area?		please describe		
	Yes No				
	Usually only if they have been referred for Acute  MI or revascularisation	15	Do any of the following factors influen	CA VC	nu in
	Offered to people with other conditions e.g.  cardiomyopathy and/or valve disease	10	offering / not offering CR to people with		
	We offer CR to all people with HF regardless of the cause		HF patients go to another CR programme in our area		
	We don't usually take people with diastolic HF		Not enough resources (e.g. time, number of staff, accommodation, transport, equipment) to open programme to this group		
4	Do you provide a Yes Go to Q4 separate programme for		HF patients are not included in our contract with the commissioners		
	the HF patients? No☐ Go to Q5		We are not confident we have right skill mix / knowledge to manage these patients		
5	If yes, are spouses/partners invited to participate in CR?  Yes □  No □		CR was not included in the locally agreed clinical guideline/pathway for people with HF		
6	Do you provide a home Yes ☐ Go to Q6		Lack of interest / referrals from local HF service clinician(s)		
·	based CR programme for No Go to Q7		The Specialist Heart Failure Nurse services already meets the patients rehab needs		
_	Managara Managara		Lack of evidence / guidance on safety		
1	If yes, which programme do you offer?  Other (please specify)  The Heart Manual The BHF Heart Failure Plan	othe reas			
		•	rtinue on		
_		need			
8	Do you provide a hospital/centre (group) based programme for HF patients?  Yes □ No □		f you would like to provide more inform comments about CR for HF, either in yo		
9	Do you offer HF patients a choice $Yes \square$ of home or centre based CR?		or in general, please add below and conveverse if needed.	ntinue	e on
10	Do you have inclusion or $Yes \square$ Go to Q10 exclusion criteria for HF? Go to Q14				
11	If yes to Q9, are these based on the NYHA No ☐ Go to Q12 Classification?	i f	We may wish to contact you again for r nformation. If you are willing to help w urther short survey please give us you	ith a	ıtact
12	Please answer the following questions on inclusion/exclusion criteria (tick all that apply)	•	email and/or telephone numbers.		
	Which NYHA Class do you include?				
	Which NYHA Class do you exclude?				

# Rehabilitation Enablement in Chronic Heart Failure: Reach HF Study

## **Follow Up Survey**

We are conducting some research funded by the National Institute of Health Research in order to develop specific cardiac rehabilitation programmes for people with chronic heart failure (HF). In 2009, you kindly completed an additional questionnaire to the NACR annual survey of cardiac rehabilitation provision and indicated you were willing to provide some more information about your service. We would be grateful if you could complete this survey and return it before the end of October 2010.**Please tick the most appropriate answer that describes your service.** 

	Cardiac Rehabilitation Centre ID number:	
	Name, Address, Email and Telephone Numb	per of the Unit
<u>De</u> i	mographics of the Rehabilitation Unit	
Q1	Where is your unit based? Tick more than one if you provide a service from the hospital and a community setting.	Q4a How many people with a primary diagnosis of HF were referred to the unit in the last 12 months covered by the 2009 NACR survey?
	In a community setting	Less than 10
	In a district general hospital	Between 10 and 50
	In a tertiary centre	Between 51 and 100
		More than 100
Q2	In which of these venues do you provide cardiac rehabilitation for people with HF?  Tick all that apply.  In an acute hospital	Q4b If known, please specify an exact number of patients who started cardiac rehab.
	In a GP Surgery	Q4c How many completed the cardiac rehab programme?
		Q5a How many patients with HF were referred because of acute MI?
		Less than 10
		Between 10 and 25
		Between 26 and 50
		Between 51 and 100
		More than 100
Q3	Please define the geographical area served your department serves?  Mainly urban	Q5b If known please specify exact number of patients who were referred because of acute MI.
	Mixed	

Q6	Do you include patients with HF and preserved ejection fraction in your CR	Q11 Do you offer only a home-based CR programme for people with Heart Failure?
	programme?	Yes Go to Q12
	Yes	No Go to Q13
	No	_
<b>~</b> 7	De constitución de la formación	Q12 Which one do you offer?
Q7	Do you have entry criteria for your programme?	Heart Manual
	Yes	BHF Heart Failure Plan
		Other, please specilfy.
	No Go to Q9	
Q8	What is the entry criteria for your programme?	
	Yes No NYHA Class	Q13 Do you offer both a home and centre-based
	Ejection Fraction	programme?
	HF patients with	Yes
	ICD's	No
	Any comments	
		Q14 What is the duration of your programme?
		Less than 6 weeks Go to Q16
		Between 6-12 weeks Go to Q16
		More than 12 weeks. Go to Q15
Q9	What are your exclusion criteria? Please	
	specify.	Q15 If more than 12 weeks
		please specify how
		long the duration of
		your programme is.
		Q16 How often are patients invited to attend?
		Once a week
		Twice a week
040	Do you offer only a control board CD	Three times a week
QTU	Do you offer only a centre-based CR programme for people with HF?	Other, please specify
	Yes	
	No	
	NO	
<b></b>	wai.a	
⊏хе	ercise	
047	B	O40 Plane Insultante assessment the
Q17	Do you provide supervised exercise in your programme for patients with HF?	Q19 Please describe the exercises used , the intensity of the exercises and comment on
	Yes	patient to staff ratio during the exercise
		sessions.
	No	
Q18	How long are the exercise sessions?	
	Up to one hour	
	Between one and two hours	
	Other	
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Q20	Do you use walking and/or other forms of normal physical activity as a method for	Q23	Do you offer a home exercise programme?  Yes
	increasing fitness - e.g. daily walking programme.		No
	Yes		
	No	Q24	Please describe and indicate if you use a specific programme such as the Heart Manual, BHF Heart Failure Plan or your own
Q21	Please describe your method below		programme.
Q22	How do you assess the exercise capacity?		
	Yes No		
	6 min Walk Test		
	Shuttle Walk Test  Other, please specify		
	Cirier, please specify		
<u>Edu</u>	<u>cation</u>		
Q25	Do you provide information about		Yes No
	Heart Failure		
	Self-Management Strategies (monitoring for fluid	d, breathing ch	anges, pain)
	Medication	, 3	
	Diet		
	Benefits		
	Household Adaptations		
<u>Psy</u>	chological Intervention		
020	Do you access anyiety and demanding	000	What cupport is offered to people with UE
Q26	Do you assess anxiety and depression?  Yes	Q28	What support is offered to people with HF who have high levels of anxiety and
	No		depression?  Referred to their GP
			Referred to their GP
Q27	What tool do you use?		Referred to CPN
	HADS		Other, please specify
	Other, please specify	l	

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Q29	Do you use a specific psychological model of intervention, e.g. motivational interviewing	Q31	Do you include any carers?	training or support for
	and 'goal' setting with regular review and resetting of new goals?		Yes	Go to Q32
	Yes		No	. Go to Q33
	No			
	, to	Q32	Please describe wha	at support you provide.
Q30	Please describe what method you use			
		Q33		ollowing data on patients rehabilitation for HF?
			First Assessment data u	Yes No using
			the NACR computer dat	tabase
			Minnesota Living with H Failure	еап
			Other, please specify	
<u>Sta</u>	<u>ffing</u>			
Q34	How many staff work in the cardiac rehal	bilitation de	partment? (Full-time	equivalents)
	1-2		<b>,</b> (	- <b>-</b>
	3-4	一		
	5-6			
	7-8			
	9 or more			
Q35	What is the composition of the staff work specify how many full-time equivalents.	king in the c	ardiac rehabilitation	department? Please
	Cardiac Rehabilitation Co-ordinator			
	Cardiac Rehabilitation Nurse			
	Heart Failure Specialist Nurse			
	Physiotherapist			
	Exercise Physiologist/Therapist			
	Occupational Therapist			
	Psychologist			
	Doctor			
	Other (please specify)			

### **Liaison with Other Services**

Q36	Where do your HF patient referrals come from? Please provide an estimated proportion.	Q41	Please indicate the estimated proportion of referrals to primary care teams
	0-24% 25-49% 50-74% >75%		0-24%
	Hospital Clinician		25-49%
	GP/Practice Nurse		50-74%
	Heart Failure Specialist Nurse		>74%
	Other, please specify		
		Q42	What do you consider as the main constraints to providing cardiac rehabilitation to all people with HF in your area?
			Financial Pressures  Lack of clinical guidelines/evidence about
Q37	Are HF specialist nurses involved in your cardiac rehab programme?		suitability
			Risk of exercise in these patients
	Yes       Go to Q38         No       Go to Q39		Other e.g. referred to palliative or end of life pathway/Specialist Heart Failure Nursing Team.  Please comment
Q38	What is their role?		
Q39	Do you refer patients with HF for long term exercise classes/Phase IV rehab?  Yes	Q43	Do you have spare capacity within your current service?  Yes
Q40	Do you refer HF patients to primary care teams for long term follow up?	Q44	Please indicate how many additional patients (per week) with HF that you could take on to your cardiac rehab programme.
	YesGo to Q41		
	No Go to Q42		

## Thank you for completing this survey

Please return questionnaires to:

Dr H Dalal, Chief Investigator REACH-HF Study Group, R&D Directorate, The Knowledge Spa, Royal Cornwall Hospitals Trust, Truro, TR1 3HD

For any queries please contact me < <u>Hayes.Dalal@3spires.cornwall.nhs.uk</u>> or Jenny Wingham <u>Jenny.Wingham@rcht.cornwall.nhs.uk</u>

#### 2011-000787

STROBE Statement—Checklist of items for *cross-sectional studies* 

#### Item No

#### Title and abstract

Patients with heart failure are not receiving cardiac rehabilitation: a national survey of the common barriers

**Objective.** To determine why so few patients with chronic heart failure in England, Wales, and Northern Ireland take part in cardiac rehabilitation

**Design**. Two stage, postal questionnaire-based, national survey.

**Population & Setting.** Stage 1: 277 cardiac rehabilitation centres that provided phase III cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register. Stage 2: 35 centres that indicated in stage 1 that they provide a separate cardiac rehabilitation programme for patients with heart failure.

Main outcome measures. N/A.

**Results.** Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure, 84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. No difference was seen in the skill mix between programmes that did or did not provide rehabilitation for patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

#### Introduction

Background/rationale

Heart failure is becoming more prevalent worldwide, mainly due to ageing of the population and improved survival after acute cardiac events. In the UK, about 900,000 people are living with heart failure. Strong evidence from meta-analyses shows that cardiac rehabilitation improves quality of life, reduces symptom burden, and reduces readmissions to hospital in patients with systolic heart failure. Current guidelines from the National Institute for Health and Clinical Excellence (NICE), American College of Cardiology (ACC)/American Heart Association (AHA), and European Society of Cardiology (ESC) recommend cardiac rehabilitation as an effective and safe intervention for heart failure. Despite the clear recommendations in the various guidelines, only a small minority of people affected by heart failure in the UK, and elsewhere, have participated in cardiac rehabilitation. Two main reasons may explain the suboptimal provision and uptake of this intervention in people with cardiac rehabilitation: the guidelines provide no specific details for healthcare planners about how and where these cardiac rehabilitation services would best be delivered, and healthcare staff involved in frontline cardiac rehabilitation services are unsure about the safety and benefits of cardiac rehabilitation in people with heart

		failure
Objectives	3	We aimed firstly to ascertain why such a small percentage of people with heart failure are receiving cardiac rehabilitation given that it is so widely acknowledged as beneficial and secondly to find out more about those centres that are providing a service specifically for heart failure. Our objective was to find out about the current provision of cardiac rehabilitation for patients with heart failure in England, Wales, and Northern Ireland
Methods		
Study design	4	Two stage, postal questionnaire-based, national survey.
Setting	5	England, Wales, and Northern Ireland, UK
Participants	6	Cardiac rehabilitation centres in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register
Variables	7	Not applicable
Data sources/ measurement	8*	Responses to two postal surveys : stage 1 and stage 2
Bias	9	Not applicable
Study size	10	277 cardiac rehabilitation centres that provided phase III cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register
Quantitative variables	11	See item 12
Statistical methods	12	We undertook frequency analyses for stages 1 and 2. We compared the results of the stage 1 questionnaire between centres that did provide separate cardiac rehabilitation programmes for HF and those that did not. We made comparisons using the test for binary data and Mann-Whitney U tests for ordinal data. We analysed data with SPSS software (version 19).
Results		
Participants	13*	Responses to all questions from the stage 1(17 items) and stage 2(44 items) national questionnaire received between October 2010 to March 2011 were analysed. This covers 81% of cardiac rehabilitation centres in England, Wales and Northern Ireland on the NACR register. The 2010 NACR report states that 60 477 patients participated in cardiac rehabilitation across the UK.
Descriptive data	14*	This data was collected only as part of the two questionnaires included as appendices to the main paper
Outcome data	15*	Not applicable
Main results	16	Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure,

84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. No difference was seen in the skill mix between programmes that did or did not provide rehabilitation for patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

Other analyses	17	Not applicable
Discussion		
Key results	18	Our survey shows that 60% of the cardiac rehabilitation centres in England, Wales, and Northern Ireland did not accept patients with heart failure, although most of those completing the survey accepted that there was good scientific evidence of benefit. Most cardiac rehabilitation centres are not implementing the latest guidance from NICE.
Limitations	19	The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate (n=17). Although we obtained detailed information about centres that provided a separate cardiac rehabilitation programme for patients with heart failure, inferences from this part of the study should be treated with caution
Interpretation	20	Commissioning groups should follow the recently developed NHS Commission's guide to coronary heart disease and the need for cardiac rehabilitation and the recently published NICE guidance on commissioning on cardiac rehabilitation for all newly diagnosed patients with chronic heart failure.
Generalisability	21	The response rate of 81% for stage 1 of our survey demonstrates the current provision of cardiac rehabilitation for patients with heart failure in England, Wales and Northern Ireland. Given the high response rate we can be confident that our findings can be extrapolated to reflect provision throughout the UK.
Other information		
Funding	22	This study was supported by a Programme Development Grant (RP-DG-0709-10111) from the National Institute for Health Research (NIHR), Department of Health, England



# Why do so few patients with heart failure participate in cardiac rehabilitation? A cross-sectional survey from England, Wales and Northern Ireland

Journal:	BMJ Open
Manuscript ID:	bmjopen-2011-000787.R1
Article Type:	Research
Date Submitted by the Author:	17-Feb-2012
Complete List of Authors:	Dalal, Hasnain; The Three Spires Medical Practice, ; Peninsula Medical school, Primary Care Wingham, Jennifer; Royal Cornwall Hospitals Trust, Research and Development; Peninsula College of Medicine and Dentistry, Graduate School Palmer, Joanne; Royal Cornwall Hospitals Trust, Research & Development Petre, Corinna; University of York, BHF Care and Education Research Group Taylor, Rod; University of York, BHF Care and Education Research Group Lewin, Robert; University of York, BHF Care and Education Research Group
 <b>Primary Subject Heading</b> :	Cardiovascular medicine
Secondary Subject Heading:	Health services research, Rehabilitation medicine
Keywords:	Adult cardiology < CARDIOLOGY, Heart failure < CARDIOLOGY, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

SCHOLARONE™ Manuscripts

# Why do so few patients with heart failure participate in cardiac rehabilitation? A cross-sectional survey from England, Wales and Northern Ireland

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Abstract: 255 words; Main text: 3008 words;

Number of figures: 1; Number of tables: 3

Supplementary files: 2 survey questionnaires

#### Summary

#### Article focus

- To determine why so few patients with chronic heart failure in England, Wales,
   and Northern Ireland take part in cardiac rehabilitation
- To find out the features of cardiac rehabilitation centres that offer a service to patients with heart failure

#### Key messages

- Most cardiac rehabilitation centres in England, Wales, and Northern Ireland do not routinely offer cardiac rehabilitation to people with chronic heart failure
- Only one in six cardiac rehabilitation centres offers a dedicated cardiac rehabilitation programme for patients with heart failure
- Those with heart failure (New York Heart Association (NYHA) stages I to III) after myocardial infarction or coronary revascularisation have the best chance of getting on a cardiac rehabilitation programme
- Lack of resources and exclusion from local commissioning agreements are seen as the main reasons for not offering cardiac rehabilitation to people with heart failure

#### Strengths and limitations

- The first comprehensive national survey of cardiac rehabilitation services for patients with heart failure, with a response rate of 84% conducted with the National Audit of Cardiac Rehabilitation (NACR)
- The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate

#### **Abstract**

**Objectives** To determine why so few patients with chronic heart failure in England, Wales, and Northern Ireland take part in cardiac rehabilitation.

**Design** Two-stage, postal questionnaire-based, national survey.

Participants and setting Stage 1: 277 cardiac rehabilitation centres that provided phase 3 cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register. Stage 2: 35 centres that indicated in stage 1 that they provide a separate cardiac rehabilitation programme for patients with heart failure.

Results Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure, 84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

**Conclusion** Patients with heart failure as a primary diagnosis are excluded from most cardiac rehabilitation programmes in England, Wales, and Northern Ireland. A lack of resources and direct exclusion from local commissioning agreements are the main barriers for not offering rehabilitation to patients with heart failure.

#### Introduction

Heart failure is becoming more prevalent worldwide, mainly due to ageing of the population and improved survival after acute cardiac events. In the UK, about 900,000 people are living with heart failure but only a small minority participate in cardiac rehabilitation. Numerous national and international evidence-based guidelines have been developed to improve diagnosis and treatment for patients with heart failure and have covered aetiology, prevention, diagnosis, and therapeutic interventions. \*\*A Exercise training has been evaluated intensively with respect to the benefit that it may provide in the treatment of those with heart failure. Evidence from meta-analyses shows that cardiac rehabilitation improves quality of life, reduces symptom burden, reduces readmissions to hospital, and may improve survival in patients with systolic heart failure. In the UK, cardiac rehabilitation has been defined as a 'multidisciplinary intervention for people with heart disease. Its main aims are to help the patient to recover as quickly and completely as possible and then to reduce to a minimum the chance of recurrence of the cardiac illness.

Current guidelines from the National Institute for Health and Clinical Excellence (NICE), American College of Cardiology (ACC)/American Heart Association (AHA), and European Society of Cardiology (ESC) recommend cardiac rehabilitation as an effective and safe intervention for heart failure. These guidelines all recommend that cardiac rehabilitation programmes should not be restricted to exercise alone but should include education, psychological input, and drug therapy; in other words, comprehensive cardiac rehabilitation to enhance self management and help patients achieve better long term management of their chronic illness.

Despite the clear recommendations in the various guidelines, only a small minority of people affected by heart failure in the UK, and elsewhere, have participated in cardiac rehabilitation. 11,12 In the UK between April 2007 and March 2008, only 1% of patients who participated in cardiac rehabilitation were referred because of heart failure, 11 and a recent European survey showed that <20% of patients with heart failure are involved in cardiac rehabilitation. 12 Two main reasons may explain the suboptimal provision and uptake of this intervention in people with cardiac rehabilitation: previous guidelines 13-15 provided no specific details for healthcare planners about how and where these cardiac rehabilitation services would best be delivered, and healthcare staff involved in frontline cardiac rehabilitation services are unsure about the safety and benefits of cardiac rehabilitation in people with heart failure. 16 Recent guidelines from Europe and North America give more detailed information on the content and provision of rehabilitation programmes in heart failure. 17,18

Most trials of cardiac rehabilitation have excluded patients with heart failure and preserved ejection fraction (diastolic heart failure), who make up 54% of the population with heart failure, and it is not clear to what extent they are specifically excluded from cardiac rehabilitation in routine practice. <sup>19</sup> In the UK, an emphasis has been placed on providing choice between hospital based rehabilitation and home based individual programmes such as the Heart Manual <sup>20</sup> after myocardial infarction, as such a choice has been shown to increase uptake. <sup>21</sup>

We conducted a two stage national survey in 2009-10. This study aimed firstly to

ascertain why such a small percentage of people with heart failure are receiving cardiac rehabilitation given that it is so widely acknowledged as beneficial and secondly to find out more about those centres that are providing a service specifically for heart failure. We therefore assessed current provision of cardiac rehabilitation for patients with heart failure in England, Wales, and Northern Ireland (stage 1) and obtained data on the features of cardiac rehabilitation centres that did offer cardiac rehabilitation for patients with heart failure (stage 2).

#### Methods

#### Stage 1

Stage 1 of the national survey included all centres that provided phase 3 rehabilitation (graduated exercise training supplemented by education on importance of medication, risk factors, diet, stress management, and relaxation training<sup>8</sup>) in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation (NACR) database funded by the British Heart Foundation. Each centre was sent a 17 item, one page postal questionnaire that asked respondents to indicate whether they routinely provided a cardiac rehabilitation service for patients with heart failure and to identify and give brief details about barriers to provision of such a service. The stage 1 questionnaire was mailed out by the NACR office in York (see appendix for the stage 1 questionnaire). To validate the data, responses from stage 1 in terms of the demographic and activity features of the centres were compared with information from the NACR (the methods and measures used by the NACR are described on and available for download from www.cardiacrehabilitation.org.uk/nacr).

#### Stage 2

Stage 2 of the survey was sent from the Royal Cornwall Hospitals Trust and included all centres that confirmed in stage 1 that they provided a separate cardiac rehabilitation service for patients with heart failure. These centres were sent a 44 item, five page questionnaire designed to find out more about the nature (patient demographics and staffing) and content of their cardiac rehabilitation service (see appendix for the stage 2 questionnaire). In the first instance, the stage 2 questionnaire was sent by email, with a letter explaining why more detailed information was being requested from the centres. To optimise response rates, non-responders were sent personalised letters with stamped addressed envelopes, and these were followed by reminder emails and telephone calls.

#### Data analysis

We entered participating centres' responses into an Excel spreadsheet. We undertook frequency analyses for stages 1 and 2. We compared the results of the stage 1 questionnaire between centres that did provide separate cardiac rehabilitation programmes for HF and those that did not. We made comparisons using the  $\chi^2$  test for binary data and Mann-Whitney U tests for ordinal data. We analysed data with SPSS software (version 19).

#### Results

#### Stage 1

Of the 277 questionnaires sent out to cardiac rehabilitation centres in England, Wales, and Northern Ireland, 232 (84%) were completed and returned (figure 1). Eight (3.4%) of these 232 centres did not respond to the first question: 'Do you

routinely offer phase 3 cardiac rehabilitation to people with heart failure?', which meant that 224 (81%) responses were eligible for full analysis. Table 1 summarises the response to the key questions in stage 1.

<<Figure 1 near here>>

<<Table 1 near here>>

Of the 224 centres with complete responses, 134 (60%) reported that they did not routinely accept people with heart failure and 90 (40%) that they did routinely offer phase 3 cardiac rehabilitation in heart failure. Of the 90 centres that did offer cardiac rehabilitation in heart failure, 39 (43%) did so only when heart failure was secondary to referral after myocardial infarction or revascularisation. Overall, only 35/224 (16%) responding centres specifically recruited patients with heart failure. Only 33/90 (37%) centres responded to a question asking about their provision of cardiac rehabilitation for patients with heart failure with preserved ejection fraction (diastolic heart failure), with only one third (11/33) taking patients from this group. Patients with heart failure and preserved ejection fraction were included in cardiac rehabilitation programmes by 11/90 (12%) centres, with 79 centres accepting only patients with systolic heart failure. Patients with New York Heart Association (NYHA) class IV disease were excluded by 53/90 (59%) centres.

Of the 90 centres that did offer cardiac rehabilitation for heart failure, 35 (39%) had a specific cardiac rehabilitation programme for this patient group. Of these, 27 (30%) offered a home based cardiac rehabilitation programme such as the Heart Manual or the British Heart Foundation's Heart Failure Plan (see footnote). Hospital-based

rehabilitation for groups was offered in 72 (80%) centres, with only 30 (33%) offering a choice between home based and centre based programmes (Table 1).

From the 134 centres that did not routinely offer rehabilitation in heart failure, 113 (84%) indicated that a lack of resources was a factor and 73 (54%) indicated that the exclusion of such a service from commissioning contracts had influenced decisions on its provision. More than half (54%) of the centres expressed confidence in the skill mix and knowledge of their staff to provide cardiac rehabilitation in heart failure.

Table 2 summarises the results of the perceived barriers given by the 90 cardiac rehabilitation centres that offer cardiac rehabilitation for heart failure. Importantly, overall 146/224 (65%) centres considered that evidence on safety was adequate and 159/224 (71%) did not believe lack of evidence on clinical benefit was an influencing factor.

<<Table 2 near here>>

Comparison between centres that did and did not provide CR in HF (some data obtained directly from the NACR database)

A higher percentage of patients diagnosed with heart failure were referred to centres that offered cardiac rehabilitation in heart failure (13 01/28 231 (4.6%)) than to those that did not (185/32 246 (0.6%)) (P<0.05). A statistically significant difference was also seen in the median number of patients referred per annum between the centres that routinely offered cardiac rehabilitation in heart failure and those that did not (287 versus 202, respectively; P=0.03). Nearly three out of four patients seen were men: 57/78 (73%) in centres offering and 85/115 (74%) in those not offering cardiac

rehabilitation in heart failure. Patients who survived myocardial infarction (8 448/28 231 (32%)) and coronary artery bypass surgery (5 047/28 231 (18%)) formed the largest proportion of patients with heart failure receiving cardiac rehabilitation. The skill mix did not differ significantly between programmes that did (n=90) or did not (n=134) offer cardiac rehabilitation except for the number of nurses. Centres not offering rehabilitation in heart failure had a mean of 2.67 (sd 1.79) whole time nurses compared to a mean of 2.24 (sd 1.85) in centres offering a dedicated rehabilitation programme in heart failure-a difference which was statistically significant (p=0.039) (Table 3).

<<Table 3 near here>>

#### Stage 2

Only 35 (16%) of the 224 respondents in stage 1 had indicated that they provided a separate cardiac rehabilitation programme for people with heart failure. Of these 35 centres, 24 (69%) agreed to provide more information about their heart failure service and were willing to participate in stage 2 of the survey. Complete stage 2 questionnaires were received from 17 (71%) of these 24 centres.

The geographical area of responding centres was mainly urban (10/17; 59%) or mixed rural and urban (7/17; 41%). The number of patients with heart failure seen annually varied widely, with 5/17 (29%) centres seeing 10–50 referred patients, 4/17 (24%) centres seeing 51–100 patients, and 3/17 (18%) seeing more than 100 patients.

Centres with dedicated cardiac rehabilitation services for heart failure were based mainly in district general hospitals (6/17; 35%) or the community (5/17; 29%) or had clinics in both settings (4/17; 24%). A combination of hospital based and home based programmes was offered by 7/17 (41%) of centres, with 8/17 (47%) offering only hospital based programmes. Seven centres offered both centre based and home based cardiac rehabilitation, and nearly half (8/17) offered only a centre based cardiac rehabilitation programme. The duration of the cardiac rehabilitation programmes offered was <6 weeks for 2/17 (12%) of centres, 6–12 weeks for 10/17 59%, and >12 weeks for 4/17 (24%). A home exercise programme was offered in 10 centres.

Supervised exercise training was a key component of almost all (16/17 (94%)) of the dedicated cardiac rehabilitation for heart failure programmes, with 11/17 (65%) centres including sessions lasting up to one hour and 5/17 (29%) including sessions of up to two hours. The content of the exercise training variably included warm-up sessions followed by aerobic exercises and resistance training with varying levels of intensity – generally three levels depending on the patient's exercise capacity assessed using rating of perceived exertion. The equipment used included exercise bikes, rowing machines, treadmills, arm bikes, cross trainers, and step up equipment. Normal physical activity (that is, walking) was used in 13/17 (76%) of centres to promote fitness. All centres provided education on heart failure, self management, medication, and diet.

Anxiety and depression were assessed by more than 80% (14/17) of centres, with 71% using the hospital anxiety and depression scale (HADS) questionnaire. More

than half of centres referred patients with high levels of anxiety and depression to their general practitioner or counsellor.

Centres that offered a dedicated rehabilitation programme in heart failure employed 3–4 whole time equivalent members of staff (7/17), with most employing cardiac rehabilitation nurses, physiotherapists, heart failure specialist nurses, and a coordinator. Few centres reported employing a psychologist (2/17) or dietician (3/17) as a member of their cardiac rehabilitation teams.

#### **Discussion**

Our survey shows that 60% of the cardiac rehabilitation centres in England, Wales, and Northern Ireland did not accept patients with heart failure, although most of those completing the survey accepted that there was good scientific evidence of benefit. This is not a new concern. The Healthcare Commission reported in 2007 that only 5.7% of 6 998 patients with heart failure surveyed were referred for cardiac rehabilitation. A recent national audit of cardiac rehabilitation in the UK reported that the cardiac rehabilitation service for heart failure was patchy or non-existent in many areas, and the 2010 NACR report states that 60 477 patients participated in cardiac rehabilitation although one in four cardiac rehabilitation centres excluded patients with heart failure and only 1% of participants were referred because of heart failure. The Healthcare Commission also reviewed progress on the implementation of the national service framework for coronary heart disease and highlighted the need to improve access and provision of cardiac rehabilitation services for people with heart failure. This implementation gap has also been reiterated by the NHS Institute for Innovation and Improvement. Most cardiac rehabilitation centres are

not implementing the latest guidance from NICE.<sup>10</sup>

Our survey aimed to discover why there is a problem with delivery. Most programme coordinators regarded the major barriers to providing a service for heart failure as local commissioning arrangements, local patient pathways, other people (for example, heart failure specialist nurses) providing a similar service, or lack of resources. Only a very small number expressed doubt about safety, their competency, or the skill mix. A significant difference was identified in the annual number of patients seen in those centres that did and did not have a dedicated heart failure programme, with larger programmes more likely to have such a programme. However, taken as a whole, no difference was seen in the staff mix of programmes that did or did not specifically recruit patients with heart failure save for the number of nurses who featured prominently and interestingly were represented in higher numbers in centres that did not offer a dedicated rehabilitation programme in heart failure. This suggests that most existing cardiac rehabilitation centres could provide such a service if commissioners were to include heart failure in the contract and only a few would require some further education or expertise. It is also noteworthy that while 60-62% of cardiac rehabilitation centres have administrative and secretarial support, less than 8% have direct involvement from a physician. Madden et al have suggested that: 'Rehabilitation might be perceived differently if presented as part of a treatment programme prescribed by cardiologists rather than as an optional lifestyle improver suggested by nurses, as is current UK practice'. 25

In contrast to the findings of the Healthcare Commission, which reported that frontline cardiac rehabilitation services are unsure about the safety and benefits of

rehabilitation in heart failure, <sup>16</sup> our survey found that a lack of evidence on safety or clinical benefit was not a factor that influenced most centres' ability to offer cardiac rehabilitation.

In this survey, only 11/90 (12%) of centres provided any support for the 54% of the heart failure population with heart failure and preserved ejection fraction. <sup>26</sup> The latter presents a similar burden to systolic heart failure in terms of healthcare costs, rehospitalisation rates, mortality, exercise intolerance, and quality of life. <sup>27–29</sup> Good evidence supports the benefits of cardiac rehabilitation in systolic heart failure in terms of quality of life, exercise capacity, reduced rates of hospital readmission related to heart failure, and potential improvements in overall survival. <sup>6,7</sup> However, the same cannot be said for heart failure with preserved ejection fraction, for which evidence is limited; research is therefore needed to assess definitively the effectiveness and cost effectiveness of exercise based cardiac rehabilitation interventions.

Patients with less severe forms of systolic heart failure (NYHA class I–III) after a heart attack or coronary revascularisation have the best chance of being offered cardiac rehabilitation. The lack of an alternative to centre based cardiac rehabilitation, because of a lack of evidence, and the lack of referral by healthcare professionals may explain why uptake of cardiac rehabilitation remains suboptimal in patients with heart failure. Offering 'real and unconstrained' choice of home based and centre based rehabilitation may help to improve the uptake of rehabilitation in heart failure, as it has in patients after myocardial infarction. <sup>21,30</sup>

The main reasons people give for not accepting an invitation to attend centre based cardiac rehabilitation classes are problems with accessibility and parking at their local hospital, a dislike of groups, and work or domestic commitments. These problems might be overcome by home based programmes, which have been introduced in an attempt to widen access and participation. Evidence on the effectiveness of home based models of cardiac rehabilitation in people with heart failure is needed so that policymakers and commissioners can decide what to provide as part of a comprehensive cardiac rehabilitation service for people with heart disease. A trial based in the UK of home exercise compared with care by a specialist heart failure nurse, without other educational elements, in patients with stable heart failure on optimised therapy failed to find a benefit in heart failure specific quality of life. However, adherence to the programme was relatively low, with participants having a large number of comorbid conditions that may have required more specialist exercise input rather than a nurse led service.

Choice in healthcare is a government priority.<sup>37</sup> One recent randomised controlled trial of cardiac rehabilitation in a rural setting used a comprehensive cohort design that allowed participants a choice of centre based or home based cardiac rehabilitation.<sup>30,38</sup> The Cornwall Heart Attack Rehabilitation Management Study (CHARMS) investigators showed that most recruited patients (55%) wanted to choose their method of cardiac rehabilitation and that outcomes did not differ between the randomised and preference arms.<sup>38</sup>

In October 2011, NICE published updated guidance on commissioning cardiac rehabilitation services to accompany the recommendations within the NICE clinical

guideline on chronic heart failure.<sup>10</sup> The advice will be linked to the outcomes and indicators specified in the NHS outcomes framework and should help 'commissioners in designing services to improve outcomes for patients and to help the NHS make better use of its resources'.<sup>39</sup>

#### Limitations of the study

The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate (n=17). Although we obtained detailed information about centres that provided a separate cardiac rehabilitation programme for patients with heart failure, inferences from this part of the study should be treated with caution.

#### Recommendations from this study

Commissioning groups should follow the recently developed NHS Commission's guide to coronary heart disease and the need for cardiac rehabilitation<sup>40</sup> and the recently published NICE guidance on commissioning on cardiac rehabilitation<sup>39</sup> for all newly diagnosed patients with chronic heart failure. Part of this guidance recommends offering all patients a choice of venue (home or hospital/centre based) for cardiac rehabilitation, although there is little evidence on the effectiveness of home based models of cardiac rehabilitation in people with heart failure, including programmes that may be suitable for patients with heart failure and preserved ejection fraction—robust evidence for these is needed.

#### **Footnotes**

The authors thank Jemma Lough for her assistance in editing the manuscript, Tony Mourant for comments on earlier drafts of the manuscript, and Christopher Hocking

for help with the literature search. The BHF Heart Failure Plan has now been replaced with An Everyday Guide to Living with Heart Failure

Contributors: RL and RST conceived the original idea of conducting the survey. HD, RST, RL, and JP wrote the paper. The survey questionnaires were designed by the BHF Care and Education Research Group at York and the REACH-HF Study Group and administered by CP via the National Audit of Cardiac Rehabilitation office in York and by JW and HD in Truro. CP and JP were involved in collating the data and data input. JP and RT analysed the data. HD and RL are joint guarantors for this study. The REACH-HF investigators include the authors HD, RL, RST, and JW, as well as Patrick Doherty, Kate Jolly, Russell Davis, Sally Singh, Jackie Austin, Robert Williams, Colin Green, Colin Greaves, Robin van Lingen, Lorna Geach and John Packard.

Funding: This study was supported by a Programme Development Grant (RP-DG-0709-10111) from the National Institute for Health Research (NIHR). The views expressed in this publication are those of the authors and not necessarily those of the NHS, NIHR, or Department of Health.

Competing interests: All authors have completed the Unified Competing Interest form at www.icmje.org/coi\_disclosure.pdf (available on request from the corresponding author) and declare that (1) none have support from commercial companies for the submitted work; (2) none have relationships with commercial companies that might have an interest in the submitted work in the previous three years; (3) their spouses, partners, or children have no financial relationships that may be relevant to the

submitted work; and (4) none have non-financial interests that may be relevant to the submitted work.

Data sharing: The Excel spreadsheets with responses from the Stage 1 and Stage 2 surveys and the data supplied by the NACR for this study will be placed in the Dryad repository and readers can access this via the DOI:xxx.

The demographic data from the centres are anonymous and the risk of identification of individual centres is low

Ethical approval: Not required.

#### References

- Adams KF. Translating heart failure guidelines into clinical practice: clinical science and the art of medicine. *Curr Cardiol Rep* 2001;3(2):130–5.
- 2. Bethell HJ, Evans JA, Turner SC, et al. The rise and fall of cardiac rehabilitation in the United Kingdom since 1998. *J Public Health (Oxf)* 2007;**29**(1):57–61.
- 3. Hunt SA, Abraham WT, Chin MH, et al. 2009 focused update incorporated Into the ACC/AHA 2005 guidelines for the diagnosis and management of heart failure in adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines developed in collaboration with the International Society for Heart and Lung Transplantation. Circulation 2009;119(14):e391–479.
- 4. Dickstein K, Cohen-Solal A, Filippatos G, et al. ESC guidelines for the diagnosis and treatment of acute and chronic heart failure 2008: the Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC

- (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). *Eur Heart J* 2008:**29**:2388–442.
- European Heart Failure Training Group. Experience from controlled trials of physical training in chronic heart failure. Protocol and patient factors in effectiveness in the improvement in exercise tolerance. *Eur Heart J* 1998;19:466–75.
- 6. Davies EJ, Rees K, Moxham T, et al. Exercise based rehabilitation for heart failure. *Eur J Heart Fail* 2010;12:706-15.
- 7. Piepoli MF, Davos C, Francis DP, et al. Exercise training meta-analysis of trials in patients with chronic heart failure (ExTraMATCH). *BMJ* 2004;328:189.
- 8. Bethell H, Lewin R, Dalal H.Cardiac rehabilitation in the United Kingdom. *Heart* 2009;95:271-5.
- NICE. Chronic heart failure. National clinical guidelines for diagnosis and management in primary and secondary care. National guideline No 5. London: Royal College of Physicians, 2003.
- NICE. Chronic heart failure. Management of chronic heart failure in adults in primary and secondary care. NICE clinical guideline CG108. London: NICE, 2010. Available at: http://guidance.nice.org.uk/nicemedia/live/13099/50514/50514.pdf (last accessed 2 September 2011).
- British Heart Foundation Cardiac Care and Education Research Group. The National Audit of Cardiac Rehabilitation. Annual statistical report 2009. BHF: London, 2009.
   Available at: www.cardiacrehabilitation.org.uk/nacr/docs/2009.pdf (last accessed 12 November 2009).
- Bjarnason-Wehrens B, McGee H, Zwisler AD, et al. Cardiac rehabilitation in Europe: results from the European Cardiac Rehabilitation Inventory Survey. Eur J Cardiovasc Prev Rehabil 2010;17(4):410–8.
- 13. Hunt SA, Baker DW, Chin MH, et al. ACC/AHA guidelines for the evaluation and management of chronic heart failure in the adult: executive summary a report of the American College of Cardiology/American Heart Association Task Force on Practice

- Guidelines (Committee to Revise the 1995 Guidelines for the Evaluation and Management of Heart Failure): developed in collaboration with the International Society for Heart and Lung Transplantation; endorsed by the Heart Failure Society of America. *Circulation* 2001;**104**(24):2996–3007.
- 14. Remme WJ, Swedberg K. Guidelines for the diagnosis and treatment of chronic heart failure. *Eur Heart J* 2001;**22**(17):1527–60.
- 15. Task Force on Heart Failure of the European Society of Cardiology. Guidelines for the diagnosis of heart failure. *Eur Heart J* 1995;**16**(6):741–51.
- 16. Healthcare Commission. *Pushing the boundaries.* London: Healthcare Commission, 2007.
- Thomas RJ, King M, Luik K, et al. AACVPR/ACC/AHA 2007 performance measures on cardiac rehabilitation for referral to and delivery of cardiac rehabilitation/secondary prevention services. *Circulation* 2007;116:1611–42.
- 18. Piepoli MF, Corrà U, Benzer W, et al. Secondary prevention through cardiac rehabilitation: from knowledge to implementation. A position paper from the Cardiac Rehabilitation Section of the European Association of Cardiovascular Prevention and Rehabilitation. Eur J Cardiovasc Prev Rehabil 2010;17:1-17.
- 19. Lam CS, Donal E, Kraigher-Krainer E, et al. Epidemiology and clinical course of heart failure with preserved ejection fraction. *Eur J Heart Fail* 2011;13:18-28.
- 20. Lewin B. Effects of self-help post-myocardial-infarction rehabilitation on psychological adjustment and use of health services. *Lancet* 1992;339:1036-40.
- 21. Dalal HM, Evans PH. Achieving national service framework standards for cardiac rehabilitation and secondary prevention. *BMJ* 2003;326:481-4.
- 22. British Heart Foundation Cardiac Care and Education Research Group. *National audit of cardiac rehabilitation. Annual statistical report 2010.* London: BHF, 2010.
- 23. Department of Health. *Coronary heart disease: national service framework for coronary heart disease.* London: DH, 2000.

24. NHS Institute for Innovation and Improvement. *Delivering quality and value. Focus on:*heart failure. Coventry: NHS Institute for Innovation and Improvement, 2009. Available
at: www.institute.nhs.uk (last accessed 11 November 2009).

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- 25. Madden M, Furze G, Lewin RJ. Complexities of patient choice in cardiac rehabilitation: qualitative findings. *J Adv Nurs* 2011;67:540-9.
- 26. Owan TE, Redfield MM. Epidemiology of diastolic heart failure. *Prog Cardiovasc Dis* 2005:47: 320-32.
- 27. Liao L, Anstrom KJ, Gottdiener JS, et al. Long-term costs and resource use in elderly participants with congestive heart failure in the Cardiovascular Health Study. *Am Heart J* 2007;153:245-52.
- Kitzman DW, Little WC, Brubaker PH, et al. Pathophysiological characterization of isolated diastolic heart failure in comparison to systolic heart failure. *JAMA* 2002;288:2144-50.
- Gottdiener JS, McClelland RL, Marshall R, et al. Outcome of congestive heart failure in elderly persons: influence of left ventricular systolic function. The Cardiovascular Health Study. *Ann Intern Med* 2002;137:631-9.
- 30. Wingham J, Dalal HM, Sweeney KG, et al. Listening to patients: choice in cardiac rehabilitation. *Eur J Cardiovasc Nurs* 2006;5:289-94.
- 31. Jones M, Jolly K, Raftery J, et al. 'DNA' may not mean 'did not participate': a qualitative study of reasons for non-adherence at home and centre-based cardiac rehabilitation.

  Fam Pract 2007;24(4):343–57.
- 32. Ades PA, Waldmann ML, McCann WJ, et al. Predictors of cardiac rehabilitation participation in older coronary patients. *Arch Intern Med* 1992;**152**(5):1033–5.
- 33. Ferguson EE. Cardiac rehabilitation an effective and comprehensive but underutilized program to reduce cardiovascular risk in patients with CVD. *US Cardiovasc Dis* 2006;**II**:14–6.
- 34. Campbell N, Grimshaw J, Rawles J, et al. Cardiac rehabilitation: the agenda set by post-myocardial infarction patients. *Health Educ J* 1994;**53**:409–20.

- 35. Pell J, Pell A, Morrison C, et al. Retrospective study of influence of deprivation on uptake of cardiac rehabilitation. *BMJ* 1996;**313**:267–8.
- 36. Jolly K, Taylor RS, Lip GY, et al. A randomized trial of the addition of home-based exercise to specialist heart failure nurse care: the Birmingham Rehabilitation Uptake Maximisation study for patients with Congestive Heart Failure (BRUM-CHF) study. Eur J Heart Fail 2009;11(2):205–13.
- 37. Lewis RQ. A new direction for NHS community services. BMJ 2006;332(7537):315.
- 38. Dalal HM, Evans PH, Campbell JL, et al. Home-based versus hospital-based rehabilitation after myocardial infarction: a randomized trial with preference arms Cornwall Heart Attack Rehabilitation Management Study (CHARMS). *Int J Cardiol* 2007;119(2):202–11.
- 39. National Institute for Health and Clinical Excellence. Advice from NICE aims to improve commissioning of services for people with chronic heart failure and for people who need cardiac rehabilitation. London: NICE, 2011. Available at: www.nice.org.uk/newsroom/pressreleases/chronicheartfailurecardiacrehabilitationcommi ssioningguides.jsp (last accessed 23 November 2011).
- 40. Department of Health. Commissioning a cardiac rehabilitation service: reabling people with coronary heart disease. London: DH, 2010. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidanc e/Browsable/DH 117504 (last accessed 23 November 2011).

**Table 1** Summary of responses to the key questions in stage 1.

Question	N	o (%) respo	nse
	Yes	No	Missing
Do you routinely offer phase III cardiac rehabilitation to people with	90	134	NA
heart failure? (n=224)	(40.1)	(59.9)	
Which of these best describes the heart failure pathway into cardiac			
rehabilitation in your area?			
Usually only if they have been referred for acute myocardial	39	12	39 (43.4)
infarction or revascularisation (n=90)	(43.3)	(13.3)	
We offer cardiac rehabilitation to all people with heart failure	56	17	17 (18.9)
regardless of the cause (n=90)	(62.2)	(18.9)	
We don't usually take people with diastolic heart failure (n=90)	11	22	57 (63.3)
	(12.2)	(24.4)	
Do you provide a separate programme for heart failure patients?	35	52	3 (3.3)
(n=90)	(38.9)	(57.8)	
If yes, are spouses/partners invited to participate in cardiac	37	29 (32.2)	24 (26.7)
rehabilitation? (n=90)	(41.1)		
Do you provide a home based cardiac rehabilitation programme for	27	56	7 (7.8)
heart failure? (n=90)	(30.0)	(62.2)	
Do you provide a hospital/centre based programme for patients with	72	15 (16.7)	3 (3.3)
heart failure? (n=90)	(80.0)		
Do you offer heart failure patients a choice of home or centre based	30	56 (62.2)	4 (4.4)
cardiac rehabilitation? (n=90)	(33.3)		
Do you offer cardiac rehabilitation to New York Heart Association	16	56 (62.2)	18 (20.0)
class IV patients? (n=90)	(17.8)		
Do any of the following factors influence you in offering/not offering			
cardiac rehabilitation to people with heart failure?			
Not enough resources (n=90)	29	50	11 (12.2)
	(32.2)	(55.6)	
HF patients are not included in our contract with the	16	54 (60.0)	20 (22.2)
commissioners (n=90)	(17.8)		
We are not confident that we have the right skill mix/knowledge	8 (8.9)	67 (74.4)	15 (16.7)
to manage these patients (n=90)			
Lack of evidence/guidance on safety (n=90)	6 (6.7)	71 (78.9)	13 (14.4)
Lack of evidence on clinical benefit (n=90)	2 (2.6)	74	14 (15.6)
		(82.2)	

NA=not applicable.

Table 2 Results of the preceived barriers to offering rehabilitation from centres that indicated they routinely offer cardiac rehabilitation in heart failure (n=90). Reasons cardiac rehabilitation programmes give for not offering cardiac rehabilitation for patients with heart failure.

Reason cited	No (%) of centres
Lack of resources	29 (32)
No contract for heart failure	16 (18)
Heart failure specialist nurse already meets cardiac rehabilitation need	14 (16)
Lack of referrals from heart failure service clinicians	11 (12)
Patients go to another cardiac rehabilitation programme in area	9 (10)
Not confident in having the correct skill mix	8 (9)

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**Table 3** Staffing mix in centres that did (n=90) and did not (n=134) offer cardiac rehabilitation for heart failure.

Discipline	Number (	Number (%) of centres	
	Offering cardiac	Not offering cardiac	
	rehabilitation for	rehabilitation for	
	heart failure	heart failure	
	(n=90)	(n=134)	
Consultant/doctor	7 (7.8)	10 (7.5)	0.186
Nurse	<u>78 (86.7)</u>	<u>119 (88.9)</u>	<u>0.039*</u>
Exercise specialist	<u>39 (43.3)</u>	<u>49 (36.6)</u>	<u>0.210</u>
Physiotherapist/exercise specialist	48 (53.3) <del>39 (43.3)</del>	<u>75 (56.0)</u> 4 <del>9 (36.6)</del>	<u>0.071</u> 0.210
Physiotherapy assistant	15 (16.7)	25 (18.7)	0.736
Dietician	46 (51.1)	70 (52.2)	0.538
Psychologist	9 (10)	13 (9.7)	0.122
Secretary/administrator	56 (62.2)	81 (60.4)	0.700
Healthcare assistant	5 (5.6)	13 (9.7)	0.587
Occupational therapist	20 (22.2)	44 (32.8)	<u>0.760</u>
<u>Pharmacist</u>	44 (48.9)	62 (46.3)	0.225
*			

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Comment [JL1]: Need to add what the \* stands for

#### **Cardiac Rehabilitation for People with Heart Failure**

1	Do you routinely offer Yes ☐ Go to Q2 Phase III cardiac	13	Is inclusion based on LV ejection fraction?	Yes	
	rehabilitation to people with heart failure?		If yes, please give %:	No	<b>u</b> ——
2	Please tick which Phases you	14	Do you have any other exclusion criteria?  If yes,	Yes No	_
3	Which of these best describes the HF pathway into CR in your area?		please describe		
	Usually only if they have been referred for Acute				
	MI or revascularisation  Offered to people with other conditions e.g.  cardiomyopathy and/or valve disease	15	Do any of the following factors influen offering / not offering CR to people wit		
	We offer CR to all people with HF regardless of the cause		HF patients go to another CR programme in our area		
4	We don't usually take people with diastolic HF		Not enough resources (e.g. time, number of staff, accommodation, transport, equipment) to open programme to this group		
4	Do you provide a Yes ☐ Go to Q4 separate programme for the HF patients? No☐ Go to Q5		HF patients are not included in our contract with the commissioners		
	the III patients.		We are not confident we have right skill mix / knowledge to manage these patients		
5	If yes, are spouses/partners invited to participate in CR?		CR was not included in the locally agreed clinical guideline/pathway for people with HF		
6	Do you provide a home Yes ☐ Go to Q6		Lack of interest / referrals from local HF service clinician(s)		
	based CR programme for No Go to Q7 HF?		The Specialist Heart Failure Nurse services already meets the patients rehab needs		
7	If yes, which programme do you offer?  Other (please specify)  The Heart Manual  The BHF Heart  Failure Plan	reve	sons tinue on		
8	Do you provide a hospital/centre (group) based programme for HF No patients?	16	f you would like to provide more inform	our ar	ea
9	Do you offer HF patients a choice of home or centre based CR?  Yes □ No □		or in general, please add below and con reverse if needed.	ntinue	∍ on
10	Do you have inclusion or exclusion criteria for HF?    Yes ☐ Go to Q10  No ☐ Go to Q14				
11	If yes to Q9, are these based on the NYHA Classification?  Yes ☐ Go to Q11  No ☐ Go to Q12	i 1	We may wish to contact you again for n nformation. If you are willing to help w further short survey please give us you	ith a	tact
12	Please answer the following questions on inclusion/exclusion criteria (tick all that apply)		email and/or telephone numbers.		
	Which NYHA Class do you include?				
	Which NYHA Class do you exclude ?				

## Rehabilitation Enablement in Chronic Heart Failure: Reach HF Study

#### **Follow Up Survey**

We are conducting some research funded by the National Institute of Health Research in order to develop specific cardiac rehabilitation programmes for people with chronic heart failure (HF). In 2009, you kindly completed an additional questionnaire to the NACR annual survey of cardiac rehabilitation provision and indicated you were willing to provide some more information about your service. We would be grateful if you could complete this survey and return it before the end of October 2010.**Please tick the most appropriate answer that describes your service.** 

	Cardiac Rehabilitation Centre ID number:	
	Name, Address, Email and Telephone Numb	per of the Unit
<u>De</u> i	mographics of the Rehabilitation Unit	
Q1	Where is your unit based? Tick more than one if you provide a service from the hospital and a community setting.	Q4a How many people with a primary diagnosis of HF were referred to the unit in the last 12 months covered by the 2009 NACR survey?
	In a community setting	Less than 10
	In a district general hospital	Between 10 and 50
	In a tertiary centre	Between 51 and 100
		More than 100
Q2	In which of these venues do you provide cardiac rehabilitation for people with HF?  Tick all that apply.  In an acute hospital	Q4b If known, please specify an exact number of patients who started cardiac rehab.
	In a GP Surgery	Q4c How many completed the cardiac rehab programme?
		Q5a How many patients with HF were referred because of acute MI?
		Less than 10
		Between 10 and 25
		Between 26 and 50
		Between 51 and 100
		More than 100
Q3	Please define the geographical area served your department serves?  Mainly urban	Q5b If known please specify exact number of patients who were referred because of acute MI.
	Mixed	

Q6	Do you include patients with HF and preserved ejection fraction in your CR programme?		Do you offer only a home-based CR programme for people with Heart Failure?		
	. •		Yes Go to Q12		
	Yes		NoGo to Q13		
	<u>—</u>	012	Which one do you offer?		
Q7	Do you have entry criteria for your	QIZ	•		
	programme?		Heart Manual		
	YesGo to Q8		BHF Heart Failure Plan		
	No Go to Q9		Other, please specilfy.		
Q8	What is the entry criteria for your programme?				
	Yes No				
	NYHA Class  Ejection Fraction	Q13	Do you offer both a home and centre-programme?	based	
	HF patients with		Yes		
	ICD's		No		
	Any comments				
		Q14	What is the duration of your program	me?	
			Less than 6 weeks Go to Q16		
			Between 6-12 weeksGo to Q16		
			More than 12 weeks. Go to Q15		
Q9	What are your exclusion criteria? Please				
	specify.	Q15	If more than 12 weeks please specify how long the duration of your programme is.		
		Q16	How often are patients invited to atter	nd?	
			Once a week		
			Twice a week		
			Three times a week		
Q10	Do you offer only a centre-based CR programme for people with HF?		Other, please specify		
	Yes				
	No				
<u>Exe</u>	ercise				
Q17	Do you provide supervised exercise in your programme for patients with HF?  Yes	Q19	Please describe the exercises used, to intensity of the exercises and comme patient to staff ratio during the exercisessions.	nt on	
	No Go to Q20				
Q18	How long are the exercise sessions?				
, 3	Up to one hour				
	Between one and two hours				
	Other				

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Q20	Do you use walking and/or other forms of	Q23	Do you offer a ho	ome exercise progi	ramme?
	normal physical activity as a method for increasing fitness - e.g. daily walking		Yes	Go to Q24	
	programme.		No	Go to Q25	
	Yes Go to Q21				
	NoGo to Q22	Q24	specific program Manual, BHF Hea	and indicate if you ime such as the He art Failure Plan or y	eart
Q21	Please describe your method below		orogramme.		
Q22	How do you assess the exercise capacity?  Yes  No				
	6 min Walk Test				
	Shuttle Walk Test  Other, please specify				
	Other, please specify				
Edu Q25	cation  Do you provide information about				
	U			Yes	No
	Heart Failure		. ,		
	Self-Management Strategies (monitoring for fluid	d, breathing ch	nges, pain)		
	Medication				
	Diet				
	Benefits				
	Household Adaptations				
<u>Psy</u>	chological Intervention				
Q26	Do you assess anxiety and depression?  Yes	Q28		offered to people vevels of anxiety and	
	No Go to Q28		-	GP	
				ınsellor	
Q27	What tool do you use?				_
	HADS		Other, please spe		
	Other, please specify			-	

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Q29	intervention, e.g. motivational interviewing carers?		Do you include any traini carers?	training or support for	
	and 'goal' setting with regular review and resetting of new goals?		Yes	So to Q32	
	Yes		<i>No</i> G	Go to Q33	
	No				
		Q32	Please describe what sup	pport you provide.	
Q30	Please describe what method you use				
		Q33	Do you collect the following who receive cardiac reha		
			First Assessment data using		
			the NACR computer database Minnesota Living with Heart		
			Failure		
			Other, please specify		
<u>Sta</u>	<u>ffing</u>				
Q34	How many staff work in the cardiac rehabi	ilitation de	partment? (Full-time equiv	/alents)	
	1-2				
	3-4				
	5-6				
	7-8				
	9 or more				
Q35	What is the composition of the staff working specify how many full-time equivalents.	ng in the c	ardiac rehabilitation depa	rtment? Please	
	Cardiac Rehabilitation Co-ordinator				
	Cardiac Rehabilitation Nurse				
	Heart Failure Specialist Nurse				
	Physiotherapist				
	Exercise Physiologist/Therapist				
	Occupational Therapist				
	Psychologist				
	Doctor				
	Other (please specify)				

**Liaison with Other Services** 

Q36	Where do your HF patient referrals come from? Please provide an estimated proportion.	Q41 Please indicate the estimated proportion of referrals to primary care teams	
	0-24% 25-49% 50-74% >75%	0-24%	
	Hospital Clinician	25-49%	
	GP/Practice Nurse	50-74%	
		>74%	
	Other, please specify		
		Q42 What do you consider as the main constrair to providing cardiac rehabilitation to all people with HF in your area?	nts
		Yes N	0
		Financial Pressures	╛
Q37	Are HF specialist nurses involved in your cardiac rehab programme?	Lack of clinical guidelines/evidence about suitability	
		Risk of exercise in these patients	
020	Yes       Go to Q38         No       Go to Q39	Other e.g. referred to palliative or end of life pathway/Specialist Heart Failure Nursing Team.  Please comment	
	Miles the steer walls O	100000000000000000000000000000000000000	
Ų38	What is their role?		
Q39	Do you refer patients with HF for long term exercise classes/Phase IV rehab?	Q43 Do you have spare capacity within your current service?	
	Yes	Yes Go to Q44	
	No	No <b>Go to End</b>	
Q40	Do you refer HF patients to primary care teams for long term follow up?	Q44 Please indicate how many additional patient (per week) with HF that you could take on to	

### Thank you for completing this survey

Please return questionnaires to:

Yes ...... Go to Q41

Dr H Dalal, Chief Investigator REACH-HF Study Group, R&D Directorate, The Knowledge Spa, Royal Cornwall Hospitals Trust, Truro, TR1 3HD

For any queries please contact me < <u>Hayes.Dalal@3spires.cornwall.nhs.uk</u>> or Jenny Wingham <u>Jenny.Wingham@rcht.cornwall.nhs.uk</u>

#### 2011-000787

STROBE Statement—Checklist of items for *cross-sectional studies* 

#### Item No

#### Title and abstract

Patients with heart failure are not receiving cardiac rehabilitation: a national survey of the common barriers

**Objective.** To determine why so few patients with chronic heart failure in England, Wales, and Northern Ireland take part in cardiac rehabilitation

**Design**. Two stage, postal questionnaire-based, national survey.

**Population & Setting.** Stage 1: 277 cardiac rehabilitation centres that provided phase III cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register. Stage 2: 35 centres that indicated in stage 1 that they provide a separate cardiac rehabilitation programme for patients with heart failure.

Main outcome measures. N/A.

Results. Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure, 84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. No difference was seen in the skill mix between programmes that did or did not provide rehabilitation for patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

#### Introduction

Background/rationale

Heart failure is becoming more prevalent worldwide, mainly due to ageing of the population and improved survival after acute cardiac events. In the UK, about 900,000 people are living with heart failure. Strong evidence from meta-analyses shows that cardiac rehabilitation improves quality of life, reduces symptom burden, and reduces readmissions to hospital in patients with systolic heart failure. Current guidelines from the National Institute for Health and Clinical Excellence (NICE), American College of Cardiology (ACC)/American Heart Association (AHA), and European Society of Cardiology (ESC) recommend cardiac rehabilitation as an effective and safe intervention for heart failure. Despite the clear recommendations in the various guidelines, only a small minority of people affected by heart failure in the UK, and elsewhere, have participated in cardiac rehabilitation. Two main reasons may explain the suboptimal provision and uptake of this intervention in people with cardiac rehabilitation: the guidelines provide no specific details for healthcare planners about how and where these cardiac rehabilitation services would best be delivered, and healthcare staff involved in frontline cardiac rehabilitation services are unsure about the safety and benefits of cardiac rehabilitation in people with heart

		failure
Objectives	3	We aimed firstly to ascertain why such a small percentage of people with heart failure are receiving cardiac rehabilitation given that it is so widely acknowledged as beneficial and secondly to find out more about those centres that are providing a service specifically for heart failure. Our objective was to find out about the current provision of cardiac rehabilitation for patients with heart failure in England, Wales, and Northern Ireland
Methods		
Study design	4	Two stage, postal questionnaire-based, national survey.
Setting	5	England, Wales, and Northern Ireland, UK
Participants	6	Cardiac rehabilitation centres in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register
Variables	7	Not applicable
Data sources/ measurement	8*	Responses to two postal surveys : stage 1 and stage 2
Bias	9	Not applicable
Study size	10	277 cardiac rehabilitation centres that provided phase III cardiac rehabilitation in England, Wales, and Northern Ireland registered on the National Audit of Cardiac Rehabilitation register
Quantitative variables	11	See item 12
Statistical methods	12	We undertook frequency analyses for stages 1 and 2. We compared the results of the stage 1 questionnaire between centres that did provide separate cardiac rehabilitation programmes for HF and those that did not. We made comparisons using the test for binary data and Mann-Whitney U tests for ordinal data. We analysed data with SPSS software (version 19).
Results		
Participants	13*	Responses to all questions from the stage 1(17 items) and stage 2(44 items) national questionnaire received between October 2010 to March 2011 were analysed. This covers 81% of cardiac rehabilitation centres in England, Wales and Northern Ireland on the NACR register. The 2010 NACR report states that 60 477 patients participated in cardiac rehabilitation across the UK.
Descriptive data	14*	This data was collected only as part of the two questionnaires included as appendices to the main paper
Outcome data	15*	Not applicable
Main results	16	Full data were available for 224/277 (81%) cardiac rehabilitation centres. Only 90/224 (40%) routinely offered phase 3 cardiac rehabilitation to patients with heart failure. Of these 90 centres that offered rehabilitation, 43% did so only when heart failure was secondary to myocardial infarction or revascularisation. Less than half (39%) had a specific rehabilitation programme for heart failure. Of those 134 centres not providing for patients with heart failure,

84% considered a lack of resources and 55% exclusion from commissioning contracts as the reason for not recruiting patients with heart failure. No difference was seen in the skill mix between programmes that did or did not provide rehabilitation for patients with heart failure. Overall, only 35/224 (16%) centres provided a separate rehabilitation programme for people with heart failure.

Other analyses	17	Not applicable
Discussion		
Key results	18	Our survey shows that 60% of the cardiac rehabilitation centres in England, Wales, and Northern Ireland did not accept patients with heart failure, although most of those completing the survey accepted that there was good scientific evidence of benefit. Most cardiac rehabilitation centres are not implementing the latest guidance from NICE.
Limitations	19	The conclusions that can be drawn from stage 2 of the survey are limited because of the low response rate (n=17). Although we obtained detailed information about centres that provided a separate cardiac rehabilitation programme for patients with heart failure, inferences from this part of the study should be treated with caution
Interpretation	20	Commissioning groups should follow the recently developed NHS Commission's guide to coronary heart disease and the need for cardiac rehabilitation and the recently published NICE guidance on commissioning on cardiac rehabilitation for all newly diagnosed patients with chronic heart failure.
Generalisability	21	The response rate of 81% for stage 1 of our survey demonstrates the current provision of cardiac rehabilitation for patients with heart failure in England, Wales and Northern Ireland. Given the high response rate we can be confident that our findings can be extrapolated to reflect provision throughout the UK.
Other information		
Funding	22	This study was supported by a Programme Development Grant (RP-DG-0709-10111) from the National Institute for Health Research (NIHR), Department of Health, England