Evaluation of Big Lottery Fund/British Heart Foundation Cardiac Rehabilitation Programme

Final Report

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Background

This is the final report of a three year evaluation of the Big Lottery Fund's (BIG) Cardiac Rehabilitation (CR) Programme, supported by the British Heart Foundation (BHF).

Cardiac Rehabilitation

CR is a multi disciplinary programme of care that helps heart patients learn how to manage the disease to reduce their chance of further problems and return to an active life. It has a 40 year history and metanalyses of more than 40 randomised trials have shown that it can reduce relative all cause mortality by 20%. In these trials people who attended also became more active, had lower blood pressure, lower cholesterol, a better BMI and were less likely to smoke than those who didn't. In some trials CR also reduced anxiety and depression and improved quality of life.

Traditionally, it has been delivered in hospital in group settings with patients attending as out patients once or twice a week for six to 12 weeks, but community and individualised home based programmes are becoming increasingly common. Programmes are changing in other ways, and recent guidelines stress that every patient should have an initial assessment of their medical, psychological and social needs and have an individualised programme made up of a 'menu' of different component parts, rather than a 'one size fits all' fixed programme that must be completed regardless of the patients' actual needs.

In 2000 the National Service Framework for Coronary Heart Disease advised that all heart patients, except those with unstable conditions, should be offered a course of cardiac rehabilitation. Results from the BHF's 2008 National Audit of Cardiac Rehabilitation show that less than 40% of patients from the three main groups of patients who are traditionally offered a place (people who have had a heart attack, undergone coronary artery bypass surgery or angioplasty) take part. The audit also revealed a post code lottery, not only for referral but also in the quality of programmes. Some have a full multidisciplinary team, nursing, physiotherapy, dietetics and psychology and others may consist of a single nurse attempting to provide help to many hundreds of patients a year.

The BIG / BHF programme

The BIG BHF Cardiac Rehabilitation programme had two main aims:

1. to increase the uptake of cardiac rehabilitation (CR) services, particularly among groups of people who currently make low use of existing services
2. to drive sustainable improvements in the quality of service patients receive.[1]

The BHF and BIG agreed a programme of work that would offer three years of pump priming funding to groups based in Primary Care who wished to improve local CR services. Following an open call for proposals and a refereeing process, 36 CR programmes in Primary Care Trusts (PCTs) in England were funded for up to three years, starting in 2005/6. Each programme was supported by one of four BHF Rehabilitation Coordinators.

There was considerable diversity in the purposes for which applications were made, examples included: working with the local authority exercise promotion workers to develop individual exercise prescriptions, to start new community based programmes, to provide a new home based opportunity for widening programmes, to enable groups that had previously not been invited to rehabilitation (e.g. angioplasty patients) to take part, and providing lessons in healthy cooking for people from ethnic minorities.

The evaluation

An evaluation was tendered by BIG and was awarded to the University of York in collaboration with the BHF Care and Education Research Group and the Social Policy Research Unit (SPRU). The evaluation was guided by a steering group that met biannually and was comprised of members from BIG, BHF, clinicians involved in CR, patient representatives and the researchers. At each meeting progress was reviewed and the data that had been analysed at that point was presented for comment.

The evaluation examined how far the programme met the twin aims: to improve uptake and to improve quality. It had three components:

- a postal survey at seven points over three years measuring progress towards the aim/s of each programme along with verbatim reports of the factors impeding or facilitating success. The aims in the protocols submitted for funding were often diverse and unclear. For the survey we worked with each programme to set between one and three targets, wherever possible in numeric terms.

- interviews with staff, patients and carers in eight sites, half of which were making good progress towards their self-defined targets and half that were behind at the point of selection;
- the recording of uptake and outcomes using the National Audit of Cardiac Rehabilitation (NACR). The NACR uses an online database to collect initial and post treatment data on every patient. More than 230 of the 360 CR programmes in the UK contribute data and all of the BIG programmes joined as part of the evaluation.

The findings from the three methods were combined to create a triangulation of findings. For example, if a programme set an aim to increase the number of women attending, using the regularly repeated survey we could ask how far they had progressed (in numbers) towards their target and by comparing this with the NACR results, we could observe if the programme was attracting more women than the other cardiac rehabilitation programmes in the UK. Interviewing the patients helped us understand how they perceived the programmes, and the staff interviews allowed us to explore if they felt they had succeeded in meeting their aims and what they felt had helped or hindered this.

Main Findings:

Aim 1 Increasing access to CR

The programme succeeded in increasing the number of patients gaining access to cardiac rehabilitation. Although we cannot be certain that some patients would not have sought out and attended a rehabilitation programme, and some programmes used the funding to provide an enhanced service rather than a completely new one, using the NACR data we estimated that the funding enabled around 10,000 additional patients to access cardiac rehabilitation over the three year period. The pump priming strategy was successful, the great majority of the programmes attracted continuing funding and we estimate, conservatively, that at least 3,000 additional patients will benefit each year. Finally, a number of programmes have used the funding as a springboard to develop further and better provision and several others were planning such improvements. Thus the funding will have a continuing and growing effect of improving access that is likely to extend for many years into the future.

Success meeting targets

Most of the programmes set out to increase uptake and 32% of them met or exceeded the initial target they had set themselves. The majority of programmes overestimated the number of patients they would treat. The interviews revealed that one of the major problems was in recruiting sufficient patients. This may seem surprising, as in surveys of patients, improving access to cardiac rehabilitation is reported as a priority. A common cause of difficulty appears to have been a lack of preparation before the applications were made. Insufficient discussion had taken place in the local health setting about which patients would be recruited to the programme, who would do this and how the new provision would fit with the existing patient pathways. Because of this, much time was taken up in the first year establishing referral pathways. The launch of the programme also coincided with a period of exceptional turmoil in Primary Care. A major reorganisation of PCTs and financial retrenchment occurred over the assessment period. As a result many of the programmes took longer to recruit staff and get started than had been anticipated, reducing the time they had available to meet their target. All of these factors help to explain the lower than predicted uptake. It is also clear that many patients, even when offered CR, do not take part, and this may have come as a surprise to those setting up new programmes causing them to overestimate the potential uptake rate. In fact, the BIG programmes had a lower refusal rate than the other programmes in the NACR dataset and there were some indications from the interviews that the initially low referral rate gave them more time and made them work harder at encouraging wavering patients to take part.

Impact on uptake in hard to reach groups

Many of the applicants mentioned that they hoped to improve uptake in groups that have been underrepresented in CR programmes. Groups mentioned were women, ethnic minorities, the elderly and those working, who are sometimes excluded because they have gone back to work before they can be offered a place on a programme. In most cases these groups continued to be hard to recruit, a fact confirmed by staff interviews, the survey and the NACR dataset. Across the 36 programmes, when compared with the other 200 programmes in the NACR dataset, there was no evidence of greater participation from: older people, those back at work, women, or from ethnic groups other than white-British, who comprised 90% of attendees. Some programmes specifically chose improving uptake in one or more of these demographic group as one of their ‘main aims’. In these programmes, only those that sought to recruit more people from ethnic backgrounds succeeded in out performing the other programmes in the NACR dataset, and most of the contribution came from one programme that had targeted women from the Indian subcontinent. It is clear that there are barriers to uptake that are not fully understood, and that simply increasing availability of programmes will not be enough.

Aim 2 Improving quality of provision

Around half of the aims set by the CR programmes that we categorised as quality aims were met, very nearly met or were exceeded. Staff interviews, and the results from the NACR, confirm that a number of key aspects of quality were significantly improved. In particular, waiting times were considerably shorter, uptake was improved and dropout from the programme reduced when the BIG sites were compared to the other programmes in the NACR dataset. There is some evidence to support the idea that this was connected with a better staff to patient ratio in BIG programmes. The better ratio was in part the result of the under recruitment, but BIG CR programmes were also typically better staffed than those in the NACR dataset. Costs (which were almost completely accounted for by staff time) were around £75 higher per patient in the BIG programmes when compared with the national median of £521. Cost per patient was still below the British Association of Cardiovascular Rehabilitations recommended level as stated in the BACR Standards.

One of the aspects of quality improvement stressed in the BIG application brief, and in many of the applications, was to improve the patients choice of venue and method of rehabilitation, mainly a choice between hospital or home delivery (the Road to Recovery Programme) or of a more local venue than the hospital. The programme significantly increased the choice of venues and methods of rehabilitation when compared to the other CR programmes in England. In the case studies, around 14% were offered a choice of CR method and round 50% were offered a choice of venue. Both methods were appreciated, but patients were equivocal about the home programme and some felt their choice of method and venue was constrained. Staff also reported problems in delivering the home programme choice.

Facilitators and barriers to success with targets

Staff perceived that being successful in both uptake and quality aims depended mostly on the personal characteristics of the frontline staff running the programmes. There was some evidence to support their view, as success with targets did not appear to be related either to how many aims were tackled, how ambitious they were, or to the number of practical problems a programme reported facing. Other problems cited included having poor access to IT, difficulty in finding suitable venues to provide the programme and poor management from above.

Clinical outcomes

The NACR dataset showed that the patients who had taken part had made very worthwhile changes in activity levels, smoking reduction, body mass index (BMI) and health related quality of life. Psychological status was also improved in those who were particularly anxious or depressed. These changes were similar to those seen in the other CR programmes of the UK, and can be predicted from previous research, to significantly reduce early mortality.

The patient and carer' perspectives

Patients. Patients greatly appreciated the help they had received and felt they had benefited. They particularly mentioned the psychological benefits, greater confidence, a feeling that they were getting support, an enhanced knowledge and awareness about their condition, as well as the chance to meet other people in the same situation. Some found solace in comparing their own relatively good health with that of the more ill patients. Around a quarter mentioned better health and an improved sense of progress and direction with their recovery. Very few specifically mentioned help with lifestyle change.

Although the great majority of patients had few overt criticisms of the help they had received, a few made suggestions as to how programmes could be improved. Some mentioned elements that should be included or that more should be made of, in particular, more psychological help, more individual tailoring of the programme and better information on some topics such as diet. Others commented on the logistics or organisation of the programme, for example the length and or timing of classes, transport problems, and a few mentioned that the support should be more seamless between discharge and CR, between the phases of CR, and after completion of a CR course. A few noted that healthcare staff sometimes gave contradictory advice or were unaware of each others activities.

Carers. They were mainly involved in taking the patients to classes and felt they benefitted in seeing the progress their relative was making, but 64% said they would have liked to have been able to be more involved in the exercise and education classes. Those who did attend the educational component appreciated it. They would have liked to be able to talk to staff privately and have information provided to them directly rather than second hand through the patient, and some would have welcomed joining in the exercise classes. Those who asked were told they could not join in because of legal liability or insufficient space in the class.

The staff perspective

The staff who were interviewed generally felt that their projects had succeeded despite the majority having failed to achieve the targets they had initially set. They felt that the main improvement was a general enhancement of the programme, with, for example, more choice for patients and an increased range of services patients could access. Staff reported an impression that some people who might not have attended were recruited due to greater flexibility of provision but acknowledged that they were finding it difficult to reach some groups of patients. A few acknowledged that the quality of the initial bids had been poor, as they underestimated the costs and the need for administrative support, and there was a lack of consideration for how they would integrate with existing resources and pathways.

Staff attributed their projects' success to the personal qualities and determination of the staff working with the patients. Where there had been less success this was usually attributed to the system in which they worked. There was evidence of some tension between different disciplines and between PCT and acute sector staff in some sites. A universal problem was staff turnover and the enormous impact on the service when a single member took leave, or was absent through sickness or maternity. The BHFs Cardiac Rehabilitation Coordinator support to staff was (almost) universally valued, especially in the initial days of the projects.

Conclusions

Despite being launched in primary care at a time of unparalleled change and financial stringency, the BIG CR programme succeeded in its aim of improving a patient's chance of accessing a CR programme, through improving the number of places and offering more choice of methods and venues. Patients made highly significant improvements in their health and wellbeing, changes that previous research has suggested may add years to their life expectancy.

A number of key indicators of quality were also improved, specifically: waiting times, recruitment and retention, better funding and offering more choice of method and venue. These improvements were most likely to have been the result of a more individualised approach to CR, a change that has long been advocated but rarely implemented. This and the other improvements appear to have been made possible by the enhanced funding observed in the BIG programmes when compared to the other programmes in the NACR dataset. Patients valued the experience very highly and had very few criticisms, mostly about the practical arrangement of the programme. The majority of carers interviewed said they would have liked the opportunity to be more involved in the process and access to more information specifically for them.

It seems highly likely that the improvement in uptake and quality seen in the first three years of the programme will continue to bear fruit. Over the years the BIG BHF CR programme may increase the number of patients who benefit from CR by many tens of thousands.

Where the programme was less successful was in recruiting specific groups traditionally thought to be underrepresented in CR. This remained true even for those programmes where this was one of the three key aims set by a programme. The four programmes aiming to improve recruitment from ethnic minorities, when taken together, did appear to improve uptake from this group although much of this improvement was from just one of the programmes.

The major difficulties reported by staff in implementing their programme were: problems with staffing (recruitment, retention and covering absences); problems establishing the referral pathways with others healthcare workers in the patients' pathway, and insufficient planning and negotiation prior to the application being made. These difficulties were often compounded by the health service ‘reforms’ taking place at this time and a financial crisis in primary care. Some degree of ‘bedding in’ and establishing credibility is probably inevitable in any newly established service. However, criticism of the applications indicated that they had often been rushed, had failed to consult the wider health community, particularly those already providing CR in secondary care, and were often not written by clinicians with experience in providing CR but by managers with unrealistic expectations. Despite the consistent reporting of these barriers across programmes at the individual programme level, the degree of success with the aims did not seem to be strongly related to the number of difficulties they faced. Interviews with the staff suggested that the degree of success was more related to the calibre, experience, drive and other personal qualities of the staff employed to deliver the programme.

Recommendations

The award process

If applicants were asked to state, in objectively measurable terms (numerical where possible), one or more targets of the project they were applying for, both the award process and the evaluation would be facilitated. Problems sometimes arose after the award because the bid had been prepared with insufficient consultation with others in the patient pathway. Applicants could be asked to specify the referral pathway and produce evidence that they have consulted more widely with significant others in that pathway.

Cardiac rehabilitation

Some of the patients felt the need for further psychological support, and evidence from the NACR dataset shows that few, if any, CR programmes had a psychologist available to them.

Some patients felt unsupported after discharge from hospital and before the CR programme started, ideally CR should be a seamless service.

Some patients felt cut off from support after the programme finished and might have benefitted from introduction to patient support groups or for those wishing to continue with exercise classes to community based exercise opportunities.

Although some centres offered a choice of venues and/or the alternative of home based rehabilitation, in reality there was only one viable choice for some patients, particularly those disadvantaged by distance or infirmity. Rehabilitation programmes should continue to develop choices of method and location.

The improvements we observed in quality were most likely to have been the result of the additional funding making more staff time available to patients. The BIG programmes were on average better funded than the other CR programmes of the UK suggesting that these too would benefit and deliver real improvements if they had greater resources.

Relatives and carers should be more involved in CR programmes. In particular they should have an opportunity to: join the classes, both educational and exercise; speak to staff privately and have information given to them directly.

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1. Introduction

This is the final report of a three year evaluation of the Big Lottery Fund's (BIG) Cardiac Rehabilitation Programme (hereafter referred to as the BIG CR Programme) carried out between July 2005 and June 2008.[*] Two interim reports published in 2006 and 2007 are available on the Big Lottery Fund website[2]. The report was compiled by the research team following discussion with members of the steering group (Appendix A).

Report structure

Section two describes the background and aims of the BIG CR programme. Section three provides a picture of the achievements of the CR programme in terms of uptake, quality and outcomes. Section four provides a more detailed insight into the performance of individual programmes and the progress they made meeting their self selected targets. Sections five, six and seven describe the views of the patients, their carers and the staff who took part. Section eight integrates and discusses the findings from the quantitative and qualitative methods used in the evaluation. Section nine outlines our final conclusions and recommendations based on the work.

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[*] Throughout this report we use the terms 'Big Lottery Fund Programme' or ‘BIG CR Programme’, to refer to the overall BIG CR Programme; the terms 'CR programme', 'project', 'site' or 'centre' are used to refer to the 36 individual CR programmes that were funded by BIG.

2. Overview of the BIG CR Programme

2.1 Cardiac rehabilitation

Cardiac rehabilitation (CR) is a life saving intervention that the Department of Health has said should be available to the majority of cardiac patients.[3] It teaches patients to be better ‘self-managers’ of their illness and ‘through their own efforts’ helps them live as full and healthy a life as possible. The most recent Cochrane review demonstrates the dramatic effect it can have on survival: patients who were randomised to attend CR had a 26% lower death rate over the next two to five years.[4]

Modern cardiac rehabilitation begins with an assessment of the patients needs, including,

- medical (medications, managing symptoms, when to seek help);
- educational (understanding the illness and how to combat it);
- lifestyle change (e.g. stopping smoking, losing weight, increasing physical activity);
- psychological (anxiety, depression, health related quality of life);
- social (return to work, social benefits, etc.).

Ideally patients and staff set goals for lifestyle change and work together to achieve them in repeated meetings or phone contacts over a period of six to12 weeks. CR can be delivered in a number of settings, currently the most common is in a group format in hospital. In recent years, the emphasis has been on moving away from hospital centred, one-size fits all programmes, towards individualised, ‘menu-based’ programmes shaped to each patient’s needs and delivered at a place and in a manner most acceptable to them. For example, offering patients a choice of home-based or hospital-based venues has been shown to improve uptake with a slight majority favouring home-based rehabilitation.[5]

Poor provision and uptake

In the UK, cardiac rehabilitation is under-provided. Less than 40% of the patients who have had a heart attack (MI) or revascularisation (angioplasty or coronary artery bypass surgery) are offered a chance to attend. Few of the patients with other conditions, such as heart failure, angina or arrhythmia take part.[6]

There is a long held suspicion that certain demographic groups are less likely to attend CR. People from ethnic minorities, the elderly, women and smokers are all groups that have been suggested as under-represented. It is not clear if this is because the services are less likely to be offered to them or because they are less interested in taking part.

It was to provide support to ameliorate these inequalities that the Big Lottery Fund and the BHF combined forces in the programme described here.

2.2 Aims of the BIG CR programme

The BIG CR Programme was one of several health initiatives funded by the Big Lottery Fund. This £4.7 million programme, supported by the British Heart Foundation (BHF), was launched in England in March 2004. It had two main priorities[1]

1. To increase the *uptake* of CR services, particularly among groups of people who currently make low use of existing services.
2. To drive *sustainable improvements in the quality of services* on offer to patients.

2.3 Commissioning of the BIG CR programmes

Funding for schemes to meet these aims was made available by the BHF, through open competition, to Primary Care Trusts (PCTs) in England. The referral process involved two expert referees scoring each application individually, followed by a meeting at which scores were compared and the expert group decided the allocation of funding. Thirty six of the applications were funded. Two applicants subsequently withdrew and the funds were reallocated. Funds requested ranged from £97,401 to £179,994. Twenty five of the 36 applications were from single PCTs and 11 were joint applications (from between two and four PCTs). A list of the 36 centres that were funded is provided in the appendices.

The CR programmes began appointing staff in February 2005 and the last began operating in October 2006.

2.4 Illustrative examples of the BIG CR programmes

The programmes were diverse and often multifaceted. To illustrate we asked five randomly chosen centres to provide a brief vignette of their programme (these should not be confused with the case study sites where the interviews were conducted).

Wakefield PCT

The project proposal was to: increase the beneficiaries of cardiac rehabilitation to include angioplasty patients; to employ a physiotherapist to support the existing community programmes, and to increase the menu of choice to patients to include a home-based programme, Road to Recovery.

The bid provided resources to:

- employ a part-time cardiac liaison nurse and physiotherapist
- incorporate the six minute walk test pre and post-programme
- review and improve the education talks and relaxation programme
- a menu of choice was increased to include hospital-based, community-based, Road to Recovery and individualised home programmes.

Overall, the project has proved to be very successful. The service has expanded over the three years since the funding began, increasing the number of patients accessing cardiac rehabilitation and making positive changes to practice. The project has been incorporated into the existing cardiac rehabilitation service.

Patient: “Cardiac Rehabilitation made me realise that life after a heart attack was not all doom and gloom, it made me appreciate that I felt fitter and healthier than I had done for many years. I also began to understand that my future was in my own hands, I was not an invalid and with common sense I could do almost anything that I wanted to do.”

North Lincolnshire PCT

Funding allowed the current cardiac rehab service to enhance its programme by providing a menu based individualised cardiac rehabilitation service. This offers people choices for cardiac rehabilitation, rather than a set programme, and targets those patients who did not access existing services; the elderly, women and those with transportation problems, by offering:

- a home-based programme using Road to Recovery
- community-based programmes in three community venues across the North Lincolnshire area (Brigg, Barton & Epworth) as well as the existing hospital-based programme

The employment of a cardiac rehabilitation nurse based in secondary care with the existing cardiac rehabilitation team led to improved communication and cross referral amongst the cardiac diseases. The employment of a British Association of Cardiac Rehabilitation Exercise Instructor in partnership with North Lincolnshire Council led to a smooth transition of community-based cardiac rehabilitation, and the establishment of Phase 4 exercise programmes in each of the community venues.

East Yorkshire PCT

Funding aided the HEARTLink Programme coordinated through a new and innovative role of a Cardiac Active Lifestyle Advisor (CALA), managed by East Riding & Hull Cardiac Rehabilitation Service. A robust working partnership was developed with the local council and multi-disciplinary teams, which led to faster, more convenient access to programmes through increased capacity and changes in ways of working.

Since the start of the community HEARTLink Programme 80 per cent of cardiac revascularisation patients have been given a programme of rehabilitation which they previously would not have had access to. Eighty two per cent of these patients have continued beyond the ten week programme and become regular users of the exercise/physical activity centre or have rejoined/joined other physical activity facilities/centres to take up different forms of exercise such as dance, local walking to health programmes and swimming groups/sessions.

HEARTLink participants in the Haltemprice Leisure Centre
with Ange Newlove 2nd Left, one of the Cardiac Active Lifestyle Advisors

Patient comments:

"This scheme gives me confidence to exercise properly and it is very encouraging to exercise with other people – that spurs you on when you feel like giving up."

"… Immediately after the operation I had a doubt about my ability to lead a full and normal life, but that has now passed. I am fitter now than I have been for 10 years and the HEARTLink sessions have played an important part in the improvement with exercise and advice. The sessions are a most important follow-up to the work of the hospital."

Salford PCT

The three year grant enabled the development of a menu of options for patients including:

- stress and weight management programmes;
- one to one with the occupational therapists and dieticians;
- counselling;
- patient approved information booklets;
- home-based rehabilitation including Road to Recovery and the Heart Manual;
- use of pedometers;
- development of an in house relaxation CD;
- close working relationships with the Healthy @ Heart Service, Angina and Heart Failure Teams, Health Improvement Teams, Salford Heart Care; the local support group and other PCT services provided to people with long term conditions;
- development of a buddy scheme offering both volunteer drivers and the befriending of people who are socially isolated;
- the development and training of healthy eating mentors

These improvements increased the number of physical activity options available across Salford from six to 21. These include exercise classes of varying levels, access to an allotment and the piloting of a water based exercise class. This has now become a mainstream service provided by Salford Community Leisure.

Western Cheshire PCT

The funding was used to help develop a partnership between Wirral Heart Beat, Ellesmere Port Fire Station (EPFS) and Chester Heart Support Group for a new venture to facilitate and promote "Partners in Health".

This venture was to facilitate:

- all suitable post myocardial infarction and post cardiac surgery patients eligible to attend CR at an outreach gym
- all patients to complete a 12 week course of individually prescribed exercise and education sessions at the facility
- improved staffing, provided by a CR nurse and a CR officer (exercise specialist)
- making the service ‘seamless’ across the patient journey
- adding new options which included women only sessions.

2.5 Commissioning of the evaluation

Following an open tendering process, the evaluation project was awarded a joint bid from the BHF Care and Education Research Group and the Social Policy Research Unit (SPRU) at the University of York.

2.6 Aims and design of the evaluation

This report addresses the following questions:

- How far did the BIG CR Programme succeed in meeting its overall aims?
- How far did individual programmes succeed in delivering their individual aims?
- What were the barriers and promoters of success as perceived by staff delivering the programme?
- What was the experience of patients and carers, from both a qualitative and quantitative viewpoint?

The questions were addressed through a three-part evaluation comprising analysis of: statistical data from the National Audit of Cardiac Rehabilitation (NACR); a rolling questionnaire survey of the 36 individual CR programmes in which quantitative data on progress towards individual, self-defined, goals was collected, and qualitative data on factors helping and hindering progress were also collected; and a more detailed examination of eight case study programmes was carried out in which qualitative data from interviews with patients, carers and staff from the purposively selected centres was collected and analysed. Full details of the methods used are provided in the appendices.

3. A quantitative perspective on uptake and access

Background

The quantitative data was gathered as part of the National Audit of Cardiac Rehabilitation (NACR) over the three years of the project. The methods are described in the appendices. As it was a year before the majority of programmes were fully operational, in the main report we have only used data from the second and third years. The use of the NACR allowed comparison with the other CR programmes in the UK, to see if they improved the uptake and the accessibility to CR.

The programmes

All the programmes were located in England as this was a condition of funding.

A few of the programmes were innovative and possibly unique, such as working with social service leisure officers or programmes specifically designed to attract patients from ethnic minorities. The great majority followed the conventional pattern, established over the last 30 years of CR, of a six to12 week programme of lifestyle change and increasing activity levels. There were no obvious differences in the profile of BIG BHF funded programmes and the others in the NACR dataset.

Almost all the programmes were designed to reach patients who had previously not attended CR because: there was no facility in easy reach or they did not like the offering, it did not cater for their needs, because it was located too far away or because they preferred a different way of working. A stipulation of the awards was that they were made to Primary Care organisations but it was clear that a proportion of these applications were written to allow the extension of an existing programme in secondary care to enable them to recruit patients who would otherwise not have attended. Thirty new programmes appeared on the register of CR programmes for the UK as a result of this funding, and there was no evidence of a drop in the number of patients seen by other programmes. Therefore we believe that the funding resulted in a genuine increase in uptake, and over the period, a conservative estimate is that there was an increase of more than 8% in the number of patients seen in CR nationally. This estimate was from NACR and the annual survey. So, although it is not possible to state with absolute confidence how much of that percentage increase was due to the BIG BHF programme, the facts presented above as well as the fact that it was a period of financial stringency in the NHS and the only major injection of funding to CR over that period was the £4.7 million from this programme, lead us to believe that a large part of the increase was the result of the BIG BHF programme. The programme also stimulated the increase in provision of CR in an indirect way. Anecdotally, we know that in several areas, the process of applying for the grants revealed the extent of the unmet needs in a local population and led to a number of new projects going ahead despite failing to win funding from the programme.

3.1 Access to CR

We can be certain that during the period of the project, at least 10,470 patients directly benefitted from BIG funding of CR. That is, they were identified as patients whose treatment was the result of the BIG CR programme on the NACR online database. For a variety of reasons, this record is less than 100% of those taking part and therefore this is probably an under representation of the actual number (Table 1).

Table 1 Number of BIG CR programme patients recorded in NACR over three years

Year	01/05/05 - 30/04/06	01/05/06 - 30/04/07	01/05/07 - 30/04/08	Total
BIG patients	2617	4522	3331	10470

3.2 Quality

Accessing hard to reach groups

One of the aims of the CR programme was to increase the uptake of those in groups traditionally regarded as underrepresented in CR.

Age and gender

The average male patient was 65 and the average female patient was 70 and they attended in similar proportions to the other CR programmes recorded in NACR (Table 2).

Table 2 Age and gender of patients attending CR in the BIG CR programmes and 'other' programmes in the UK

	01/05/06 - 30/04/07				01/05/07 - 30/04/08			
	Other		BIG Patients		Other		BIG Patients	
	Average Age	%	Average Age	%	Average Age	%	Average Age	%
Male	65	69.7	66	71.2	65	70.2	66	71.8
Female	70	30.3	70	28.8	71	29.8	70	28.2

Employment

As is clear from table 3, there were statistically significant differences between the employment status of the BIG patients and the other programmes in the UK in both years, and slightly fewer of the BIG patients were employed and more were retired.

Table 3 Employment status of patients in the BIG CR programmes and 'other' CR programmes in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Retired	57.5%	59.5%	57.6%	59.1%
Employed - Full time	18.3%	15.9%	18.7%	15.5%
Temporarily sick or injured	6.5%	7.0%	6.5%	5.8%
Permanently sick/disabled	4.8%	4.7%	4.1%	4.0%
Self employed - full time	3.8%	4.5%	4.0%	4.7%
Employed - part time	3.9%	3.7%	3.6%	4.9%
Looking after family/home	1.8%	1.4%	2.0%	2.2%
Self employed - part time	1.5%	2.2%	1.4%	2.3%
Unemployed looking for work	1.1%	0.6%	1.4%	0.9%
Other reasons for not working	0.8%	0.4%	0.6%	0.5%
Student	0.1%	0.1%	0.1%	0.2%

Ethnicity

Across all the BIG CR Programmes, there were significantly more white British (92% vs. 74%) than the other CR programmes, and fewer Pakistani attendees (.3% vs 3%) but a higher proportion of Indian patients (2.5% vs 1.7%) (Table 4).

Table 4 Ethnicity of those in the BIG CR programmes and 'other' CR programmes in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG patients	Other	BIG patients
White (British)	74.3%	89.3%	73.3%	92.1%
White (Other)	1.9%	0.7%	2.4%	0.8%
White (Irish)	1.1%	1.1%	1.5%	1.4%
Pakistani	3.7%	0.7%	3.9%	0.4%
Indian	1.6%	4.2%	1.6%	2.4%
Other Asian	0.6%	0.7%	0.5%	0.4%
Other Ethnic Group	0.6%	0.3%	0.4%	0.1%
Black Caribbean	0.3%	0.4%	0.3%	0.2%
Bangladeshi	0.2%	0.1%	0.3%	0.2%
Black African	0.1%	0.1%	0.1%	<0.1%
Mixed Other	0.1%	<0.1%	0.1%	0.0%
Mixed White/Black Caribbean	0.1%	0.1%	0.1%	0.0%
Chinese	0.1%	<0.1%	0.1%	<0.1%
Mixed White/Asian	<0.1%	0.0%	0.1%	<0.1%
Black Other	<0.1%	<0.1%	0.1%	0.0%
Mixed White/Black African	<0.1%	<0.1%	0.0%	0.0%
Not stated	15.3%	2.0%	15.2%	1.9%

Health

More of the BIG patients had had previous bypass surgery and a diagnosis of heart failure or angina than those attending other CR programmes, suggesting they may have had a greater burden of coronary artery disease (Table 5).

Table 5 Percentage of patients with previous cardiac events in the BIG CR programmes and in the 'other' CR programmes in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Myocardial Infarction	18.7%	19.0%	17.7%	18.2%
Acute Coronary Syndrome	1.5%	2.0%*	1.4%	1.6%
Bypass surgery	4.4%	6.2%*	4.3%	5.5%*
Angioplasty	5.9%	7.7%*	6.5%	7.6%*
Cardiac arrest	2.4%	1.2%*	2.1%	1.4%*
Angina	15.5%	29.2%*	16.7%	25.5%*
Other surgery	1.6%	2.3%*	1.3%	1.4%
Heart failure	1.9%	2.5%*	1.6%	2.5%*

** Statistically significant differences* (all $p<0.5$ or greater) *between BIG and other patients*

However they were statistically significantly less likely, in both years of the evaluation, to have arthritis, stroke, asthma, emphysema hypertension or an unspecified chronic condition (Table 6) than patients in the other CR programmes in the UK. In the first year, more BIG patients entering CR had angina, but less in the second year. Although these differences were statistically significant, the differences in percentages were slight and in clinical terms the two groups were very similar.

Table 6 Percentage of patients undertaking cardiac rehabilitation who have various co-morbidities in the BIG CR programmes and the 'other' CR programmes in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Angina	35.1%	42.2%*	35.4%	33.3%*
Arthritis	20.8%	19.9%	17.4%	14.6%*
Diabetes	19.8%	17.5%*	19.9%	15.6%*
Rheumatism	5.2%	5.2%	4.2%	3.6%
Stroke	6.4%	5.7%	5.9%	4.5%*
Osteoporosis	3.5%	2.9%	2.7%	2.7%
Chronic bronchitis	3.5%	2.8%*	2.9%	2.2%*
Emphysema	2.6%	1.6%*	2.3%	1.1%*
Asthma	12.3%	9.6%*	11.3%	8.3%*
Claudication	6.6%	6.7%	5.6%	5.5%
Chronic Back	13.7%	14.2%	11.0%	10.9%
Hypertension	44.4%	39.8%*	46.0%	37.0%*
Cancer	6.7%	4.9%*	6.2%	5.9%
Other Complaint	32.8%	24.8%*	31.4%	21.5%*

** denotes statistically significant difference (all $p<0.05$ or greater)*

Reason for attending

For around half the patients attending CR due to a heart attack (MI), there was a significantly higher percentage of patients referred after by-pass surgery or angioplasty (Table 7) than in other rehabilitation programmes, a reflection of the fact that several centres had applied for funding to be able to offer these patients CR.

Table 7 Reasons for referral to CR as a percentage of all referrals in BIG CR programmes and the 'other' CR sites in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Myocardial Infarction	46.1%	35.3%	41.4%	37.8%
MI with PCI	4.3%	5.7%	5.7%	7.8%
MI with recent PCI	2.1%	5.6%	2.5%	4.0%
Total MI	52.5%	46.6%	49.6	49.6
Acute Coronary Syndrome	6.3%	1.4%	4.9%	1.7%
Bypass surgery	15.0%	21.5%	16.1%	21.1%
Transplant	<0.1%	<0.1%	<0.1%	0.0%
Other surgery	4.8%	3.1%	5.5%	5.0%
Angioplasty	12.7%	22.1%	15.2%	18.5%
Cardiac arrest	0.3%	0.1%	0.2%	0.2%
Angina	3.8%	2.1%	3.9%	1.4%
Heart failure	1.1%	0.4%	0.8%	0.7%
Pacemaker	0.1%	0.1%	0.1%	<0.1%
ICD	0.3%	0.1%	0.2%	0.2%
LV assist device	<0.1%	0.0%	<0.1%	<0.1%
Congenital Heart	0.1%	<0.1%	<0.1%	0.0%

Taken as a whole, there seemed to have been little effect on the percentage of the elderly, women, people from ethnic minorities or those at work who took part, as compared to the other programmes in the UK.

Uptake in programmes that specifically targeted certain groups

However, the aims of the different programmes varied widely, and not all had set out to change these aspects of recruitment. Therefore, we analysed separately the uptake figures for those programmes that specifically sought to: improve the uptake amongst older people (six programmes), improve the uptake for non white-British patients (three programmes), for women (four programmes) and for those in employment (two programmes).

Six sites had set targeting older people as an aim of the programme but comparing the number of people over 75 in those centres, and those in other programmes, did not reveal a significant difference. There was some suggestion of a trend towards the number of elderly in BIG centres increasing over time, but by the end of the assessment this had not quite reached statistical significance (linear by linear association, p=0.069) (see Table 8 below).

Table 8 Older People

	01/05/05-30/04/06		01/05/06-30/04/07		01/05/07-30/04/08	
	Other	BIG	Other	BIG	Other	BIG
% over 75	43.3%	41.6%	43.2%	42.9%	43.3%	46.0%

Three centres specifically targeted non white British patients and there was a statistically significant difference in the number of these patients attending BIG programmes, with more non white patients attending (see Table 9 below).

Table 9 Non white British (three sites)

	01/05/05-30/04/06		01/05/06-30/04/07		01/05/07-30/04/08	
	Other	BIG	Other	BIG	Other	BIG
% non white British	6.3	24.5	10.4	38.0	11.5	23.0
% white British	81.5	75.5	74.3	60.4	73.3	76.4
% not stated	12.2	0	15.3	1.6	15.2	0.7

Four sites targeted the recruitment of women, but compared to the rest of the CR centres reporting to NACR, they had a lower percentage of women attending. This showed no trend in improving over the assessment period (see Table 10 below).

Table 10 Women (four sites)

	01/05/05-30/04/06		01/05/06-30/04/07		01/05/07-30/04/08	
	Other	BIG	Other	BIG	Other	BIG
% women	30.7%	25.6%	30.3%	26.8%	29.8%	25.4%

Two sites tried to increase the number of people going back to work, a group that often misses out, especially if there is a waiting time before the programme starts.

They did not appear to achieve this aim when compared with the other programmes in NACR (Table 11).

Table 11 Employed (two sites)

	01/05/05-30/04/06		01/05/06-30/04/07		01/05/07-30/04/08	
	Other	BIG	Other	BIG	Other	BIG
% employed	25.3%	24.9%	27.7%	31.2%	27.8%	28.9%

Other aspects of quality

Waiting time

One of the most marked differences between BIG sites and the UK sites was a significantly shorter waiting time. The time to referral following the acute cardiac event was the same, but the waiting time was significantly lower, for example in the case of bypass surgery it was 22 vs 56 days (Table 12).

Table 12 Waiting list time from the acute event to referral and from referral to joining a rehabilitation programme

Median time from event to referral (days)

	01/05/05 - 30/04/06		01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG	Other	BIG	Other	BIG
Myocardial Infarction	4	4	3	4	3	4
Bypass surgery	11	11	9	11	8	11
Angioplasty	5	2	3	4	1	4
ALL	5	5	4	6	4	6

Median time on the waiting list for a cardiac rehabilitation programme (days)

Myocardial Infarction	39	12	27.5	9	18	10
Bypass surgery	58	27	56	24.5	56	22
Angioplasty	43	20	35	16	34	13
ALL	47	20	38	16	33	16

Non attendance

Non attendance is another important marker of quality and one of the main drivers of poor uptake. The great majority of patients have a lot to gain from CR and it is important that they attend and are encouraged to do so. BIG CR programmes had fewer patients not attending than the other CR programmes in the UK (17.5% vs 27%) (Table 13).

Table 13 The number of patients offered rehabilitation who did not take part over the last two years

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Did not take part	11559 (27%)	753 (17%)	17470 (27%)	622 (19%)

The NACR asked for the reason for non-attendance. In many cases staff have no further contact with patients who do not choose to take up the invitation and this data must be treated with some care.

Table14 Reasons given for patients not taking part

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Patient not interested/refused	31%	44%	32%	33%
Physical incapacity	11%	14%	15%	23%
Too ill	7%	8%	5%	14%
Ongoing investigation	5%	3%	6%	3%
Not referred	5%	1%	3%	<1%
Local exclusion criteria	4%	2%	3%	1%
Too far to travel	2%	2%	3%	3%
Returned to work	3%	2%	3%	2%
Mental incapacity	1%	1%	2%	3%
Holidaymaker	1%	1%	1%	1%
No transport	1%	1%	1%	<1%
Language barrier	<1%	<1%	1%	<1%

Components offered

There were slight differences in what patients accessed in the BIG CR Programmes compared to the other programmes in the UK. Fewer took part in any exercise programme and more had talks or a video about lifestyle. Many of these differences may have been due to the use of the BHFs Road to Recovery Programme in the BIG sites, which delivers the multi-disciplinary elements through written materials and DVDs (Table 15).

Table 15 The type of sessions and the percentage taking part in the BIG CR Programmes and the 'other' programmes in the UK over the last two years (% of those attending rehab)

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG Patients	Other	BIG Patients
Group Exercise	67.3%	46.0%	61.4%	41.8%
Individual Exercise	34.6%	23.3%	28.1%	27.9%
Home Exercise	44.4%	21.1%	36.7%	29.4%
Lifestyle - written	76.7%	65.8%	77.3%	70.2%
Lifestyle - talk/video	63.8%	66.8%	59.8%	65.3%
Diet - Group	48.8%	27.3%	43.1%	32.3%
Diet - Individual	41.4%	22.7%	39.8%	29.1%

3.3 Outcomes and benefits for patients

Medical and lifestyle

Patients in BIG and the other UK programmes, made statistically, and in several cases clinically, significant improvements to their lifestyle, in particular becoming more active, improving their BMI, being less likely to smoke, and being less anxious and/or depressed.

Table 16 Outcomes of patients taking part in CR in BIG CR programmes and the 'other' CR programmes in the UK over the last two years

		01/05/06 - 30/04/07			01/05/07 - 30/04/08		
		Before (%)	After (%)	Change (%)	Before (%)	After (%)	Change (%)
BMI <30	Other CR	73.2	73.6	+0.4	74.0	74.4	+0.4
	BIG	73.6	74.8	+1.2	73.5	74.3	+0.8
Exercise 5 x 30 mins/week	Other CR	35.0	55.8	+20.8	33.2	52.5	+19.3
	BIG	35.9	53.7	+17.8	39.0	56.9	+17.9
Smokers	Other CR	13.2	8.0	-5.2	12.2	7.3	-4.9
	BIG	13.9	7.7	-6.2	12.6	6.1	-6.5
HADS –anxiety - Normal	Other CR	70.8	76.3	+5.5	72.3	76.7	+4.4
	BIG	68.3	72.3	+4.0	72.4	76.4	+4.0
HADS –anxiety - borderline	Other CR	16.9	14.0	-2.9	16.3	14.4	-1.9
	BIG	18.5	16.4	-2.1	14.8	13.1	-1.7
HADS –anxiety - Clinically anxious	Other CR	12.3	9.7	-2.6	11.5	8.9	-2.6
	BIG	13.2	11.3	-1.9	12.9	10.4	-2.5
HADS – depression - normal	Other CR	83.2	86.6	3.4	83.9	87.3	+3.4
	BIG	81.3	83.7	2.4	82.2	85.7	+3.5
HADS –	Other CR	10.8	8.7	-2.1	10.7	8.6	-2.1

depression – borderline	BIG	11.0	9.6	-1.4	10.7	9.5	-1.2
HADS – depression clinically depressed	Other CR	6.0	4.7	-1.3	5.3	4.0	-1.3
	BIG	7.6	6.8	-0.8	7.0	4.9	-2.1

Quality of life

Both BIG and the other CR programmes produced the expected gains in health related quality of life as demonstrated by the changes in scores on the Dartmouth Coop Scales (Table 17). These scales consist of a total of nine charts, where four focus on specific functional health areas, three capture the dimension of overall health and two are concerned with quality of life issues. The most notable change between the BIG CR programmes and the other CR programmes was that there was a much larger shift in social support. A negative change indicates being less dependent on others, not a loss of social support, and then only in the second year.

Table 17 Before and after CR scores on the Dartmouth Coop Quality of Life Scale for patients attending BIG CR programmes and the 'other' CR programmes of the UK over the last two years.

		01/05/06 - 30/04/07*			01/05/07 - 30/04/08		
		Before (%)	After (%)	Change (%)	Before (%)	After (%)	Change (%)
Physical Fitness	Other CR	40.8	66.2	25.6	41.4	69.0	27.6
	BIG	40.6	61.4	20.8	39.9	65.4	25.5
Feelings	Other CR	83.5	87.9	4.4	84.3	88.9	4.6
	BIG	81.9	85.7	3.8	85.2	88.5	3.3
Daily Activities	Other CR	84.5	93.4	8.9	84.8	94.4	9.6
	BIG	82.5	90.0	7.5	84.0	93.4	9.4
Social Activities	Other CR	80.3	91.3	11.0	81.6	92.5	10.9
	BIG	79.5	88.7	9.2	77.1	90.9	13.8
Social Support	Other CR	88.5	86.1	-2.4	88.6	87.2	-1.4
	BIG	89.4	85.3	-4.1	91.6	84.2	-7.4
Pain	Other CR	75.0	81.1	6.1	77.0	82.7	5.7
	BIG	75.7	78.5	2.8	74.5	80.8	6.3
Overall Health	Other CR	66.9	76.4	9.5	67.9	78.8	10.9
	BIG	64.0	72.3	8.3	66.2	75.1	8.9
Quality of life	Other CR	94.1	96.5	2.4	94.8	97.1	2.3
	BIG	93.0	95.5	2.5	93.6	96.3	2.7

Budget and cost per patient

From the available data we were able to calculate the budget per patient for 33% of BIG sites (22% for other sites) and the cost per patient of 67% for BIG sites (66% for other sites). The median budget per patient for BIG sites was £36 higher and the cost per patient was £75 higher than other sites. Due to missing data these figures should be treated with some caution.

Table 18 Budget per patient and cost per patient treated in BIG CR programmes and the 'other' CR programmes in the UK: April 2006-March 2007

	£ BIG	£ Other
Budget per patient		
Median	£509	£473
Interquartile range	286 to 847	303 to 766
Cost per patient treated		
Median	£521	£446
Interquartile range	290 to 910	296 to 773

Staffing

The mean number of staff in BIG programmes was the same (Table 19) but as Table 20 shows, there were differences in the kinds of staff. Notably all programmes had a nurse but fewer had a dietician, occupational therapist, physiotherapist or pharmacist. Once again this may be because of the greater use of the Road to Recovery, or it may be because the first three of these are less commonly found in primary care.

Table 19 The mean, median and range in the number of professions per programme in the BIG CR Programmes and the 'other' CR programmes in the UK

	BIG Lottery	Other programmes
Mean	4	4
Median	4	4
Range	2-7	1-9

Table 20 The percentage of programmes which mentioned access to each profession

Profession	BIG programmes %	Others in NACR %
% answering the question	91	81
Nurse	100	95
Physiotherapist	55	72
Secretarial / Admin	68	56
Dietician	39	56
Pharmacist	19	47
Occupational therapist	7	29
Psychologist	26	23
Physical activity / Exercise specialist*	52	25
Fitness Instructor	23	10
Physiologist / Sports Scientist	10	12
Exercise Specialist	19	7
BACR Instructor	3	2
Administrator / Coordinator	19	10
Counsellor	7	5
Healthcare Assistant	3	4
Social worker	0	2
Doctor	0	2

* Some programmes mentioned more than one type of exercise specialist

Dropout

One marker of the quality of a programme is the number of patients who complete the programme. Some have dropout rates of nearly 50% within three weeks of a six week programme. As Table 21 shows, in the final year of the assessment almost half as many patients again completed a BIG programme as completed the other CR programmes in the UK.

Table 21. Percentage of patients who completed rehab in the BIG CR programmes and the ‘other’ CR programmes in the UK

	01/05/06 - 30/04/07		01/05/07 - 30/04/08	
	Other	BIG	Other	BIG
% Completing rehab	30.4%	37.1%	24.4%	36.8%

4. A Service Perspective

In order to assess the achievements of the 36 programmes both individually and collectively, the centres were asked to define their main goals in numerical terms and progress towards them was reported via a questionnaire issued at seven survey points over three years. There was a good overall response rate to this rolling survey, exceeding 83% at six of the seven rounds carried out. The quantitative data was also used to select the case studies for more in-depth study using qualitative methods, based on their performance to the third round of the survey. Further description of the method is provided in the appendices.

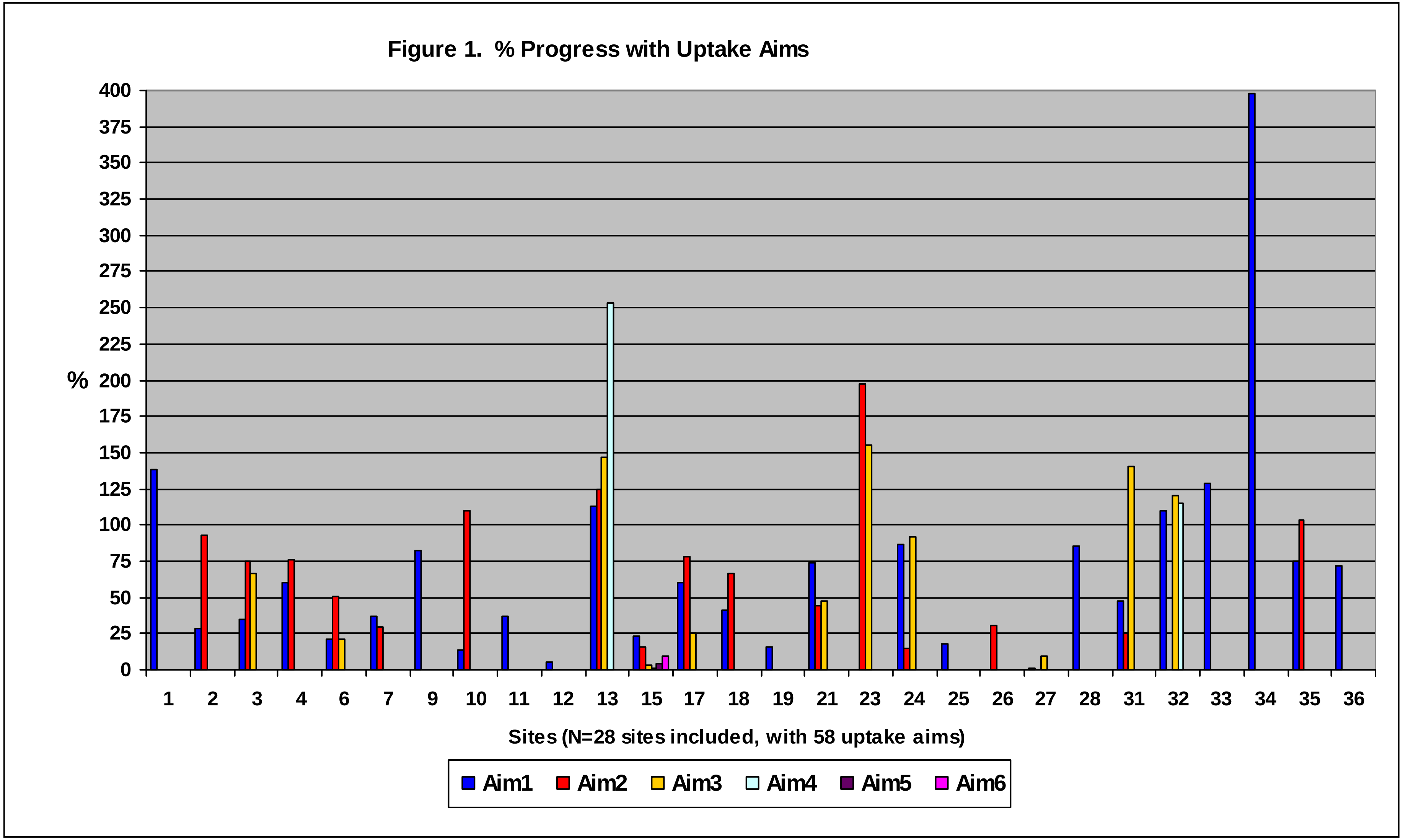
4.1 Did the CR programmes achieve their individual aims?

Uptake aims

The twenty eight centres who provided complete data, defined a total of 58 aims relating to uptake. Most of the sites self-defined between one and three aims (see Figure 1).

Examples of uptake aims

- We hope that 532 patients will have used the home-based programme by the end of the project.
- We hope to increase uptake of CR from 700 patients per annum in 2004 to 1100 patients per annum by the end of the project.
- By the end of the project, we hope to increase the use of the home exercise programme from 24 patients per annum in 2004, to 176 patients per annum. For patients aged over 65yrs, from 25 to 110 per annum. For women, from six per annum in 2004 to 142 per annum. For ethnic minority groups, from16 per annum in 2004 to 246 per annum.
- We hope that 90 people from West of the City will use the group exercise programme by the end of the project.
- We hope that 150 patients will have been enrolled in the 'Walking for Health' program by the end of the project.



Note: The numbers refer to the site's identity code.

Twenty six percent (15/58) of the aims relating to uptake were met or exceeded (see Table 22). A third of the centres (32%, 9/28) achieved one or more of their aims. Some targets were dramatically out-performed, for example one centre achieved four times their aim at recruiting patients (597 vs the aim of 150). Another centre more than met its targets on two out of its three uptake aims, while yet another centre progressed well on all four of its aims (although three were relatively modest targets compared to those set by many of the sites).

Table 22 The number of uptake aims that were met/exceeded and the % above target (n=15/58 aims).

Percentage bracket	**Aims N=**
150% and above	4
130-149%	3
100-129%	8
	15

Conversely, 74% (43/58) of the aims relating to uptake were not fully achieved. Table 23 shows the range of under-achievement in percentage bands.

Table 23 Range of percentage progress scores for all uptake aims that were not fully met (N= 43/58 aims).

Percentage bracket	**Aims N=**
60-99%	15
30-59%	10
0-29%	18
	43

Less than 10% of the targets were achieved for six aims specified by three sites, including one site where three of its six aims achieved less than 10% progress. Overall, the worst scores were obtained by two sites, with one only managing to get two out of 198 anticipated MI patients using the Heart Manual, and the other site only fast-tracking one out of 200 anticipated patients from Phase III to Phase IV by the time of the final survey.

Quality aims

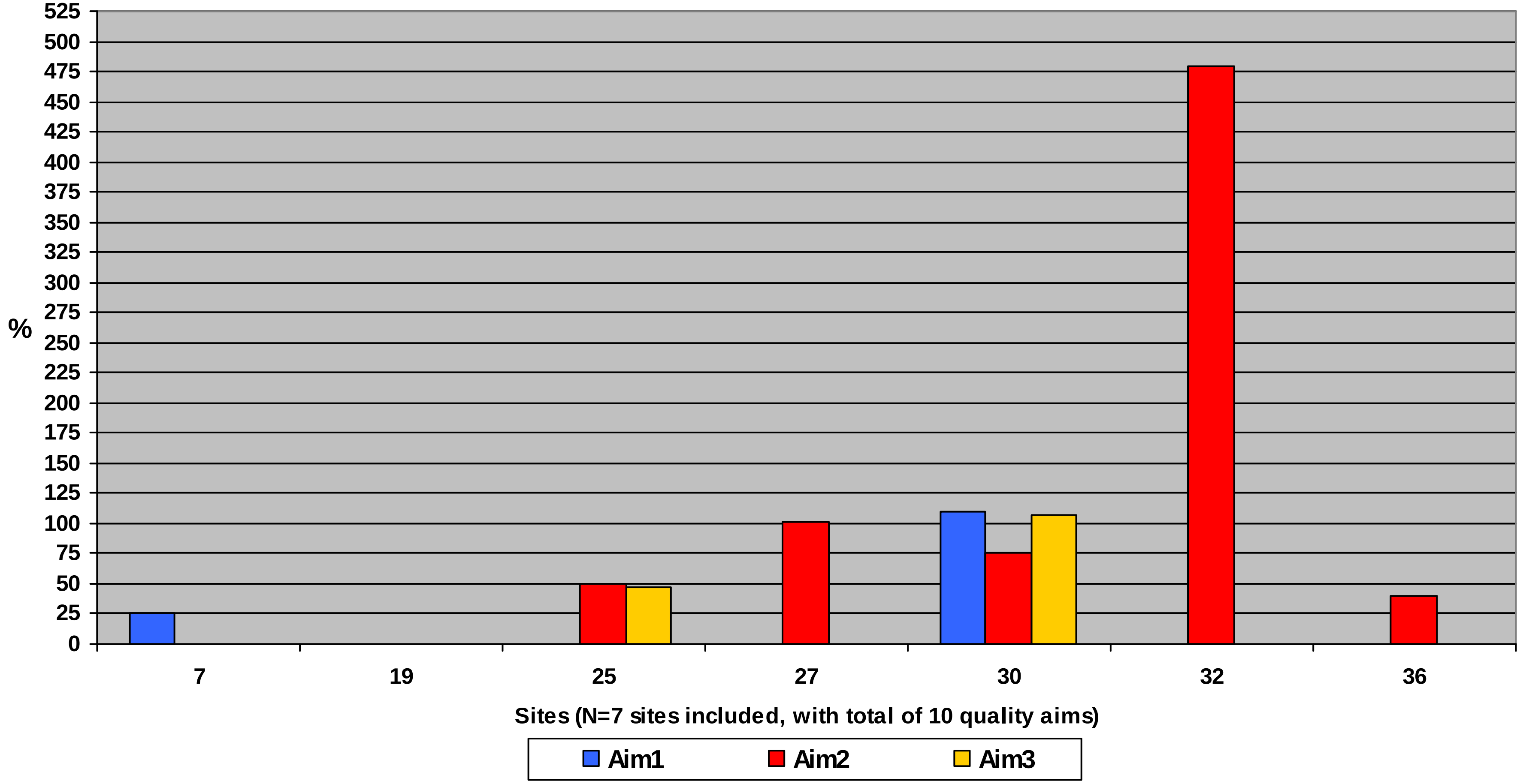
Seven sites chose to define a total of 10 quality aims. Up to three quality aims were specified by these sites.

Examples of quality targets

- We hope to improve access by providing a wider choice of venues/ programmes from four venues per annum in 2004 to 10 per annum by the end of the project.
- We hope to have created three additional programs by the end of the project.
- We hope to reduce CR waiting list from 12 weeks to nine weeks by the end of the project.
- By the end of the project we hope to have offered the choice of options to 1100 patients.
- We hope to train four Cardiac Rehabilitation teams in the North Central Sector in Self Management by the end of the project.
- We hope that 90% of patients prior to PCI will have been offered rehab information by the end of the project.

The percentage progress towards quality targets is shown in Figure 2.

Figure 2: % Progress with quality aims



Note: Numbers are the site identity code. Site 19 was unable to provide sufficient data to complete this part of the assessment

Of the 10 aims specified, four were met or exceeded by three sites, and six were not fully met by five sites (see Table 24). Again, some sites performed well across all of their aims while others did poorly. The four aims that were reached included all three aims of one site.

Overall, the progress scores for quality targets ranged from 480% to 0%. The top score was achieved by a site that aimed to hold 50 education classes but eventually held 240. The lowest score was obtained by a site that had aimed to develop a referral protocol by the end of the project but which had not at the time of the final survey.

Table 24 Percentage progress scores for all quality aims that were met and were not fully met (n=10)

Percentage bracket	Aims
100% - and above	4
60% - 99%	1
30% - 59%	3
0% - 29%	2
	10

4.2 What helped and what hindered progress with the aims?

At each survey point, respondents were invited to briefly comment on what had helped and/or hindered their progress towards each of their targets, both quality and uptake. A wide range of factors were identified. These were examined across the 35 sites and over the three years of the BIG CR Programme. In the analysis we sought to identify the most common factors that helped or hindered progress across all the sites, and we looked for any notable differences in factors affecting sites that met one or more of their targets versus those that did not. We also looked for any factors that were influential at particular points in time in the life-course of the programmes.

Factors that helped progress

The factors most commonly identified by respondents as having helped their programme progress over time are summarised in Table 25.

Table 25 Factors that helped progress

Rank	Factor	N sites (total = 35)
1	Qualities of CR team/CR staff support (knowledge, skills, and personal qualities - commitment, enthusiasm, dedication)	18
2	Communication/relationships with other staff	14
3	Referrals (systems, number of patients available)	12
4	Staff clinical background, experience, skills, versatility (including having staff who speak other languages)	11
5	Networking/links within the pathway	9
6=	Joint working and partnerships	5
6=	Good contact with patients (face to face recruitment, phoning, writing, recruitment via ward staff, information packs)	5
8	Promotion in local health economies, growing awareness of service locally	4
9	Teamwork across project and health economy	3
	Other factors mentioned: having staff in post, getting venues going; getting equipment; having training; offering patients more options; attending meetings; good staffing levels/low absences; help from patient representatives/support groups; widening criteria; not having to send data to evaluation as often; getting packs; holding extra sessions; job sharing; holding discharge sessions; having accessible venues; getting positive feedback; patients co-operation.	

Qualities of staff and working relationships

Several of these factors relate to the qualities of staff in the CR teams and the working relationships established with partners and patients. These factors were mentioned at intervals throughout the BIG CR programme’s set up and operation, and were not tied to any stage of the project. They were influential in both keeping programmes running to plan and in overcoming some of the problems encountered over time. These factors were reported as facilitators by both centres that had progressed well and centres that had done less well.

Factors that hindered progress

A more diverse range of factors were identified by respondents as having hindered sites' progress (see Table 26). Again, these barriers were reported by many of the sites regardless of success. None of the negative factors were particular to sites that had not met one or more their targets.

Table 26 Factors that hindered progress

Rank	**Factor**	**N sites (total = 35)**
1	CR staffing (availability, sickness, annual leave, maternity leave, delays in appointments, CRB checks, job freezes)	31
2	Lack of patients (low numbers, unsuitable patients, referral issues, referrals outside criteria, low uptake, fewer patients having the procedure, drop in admissions)	22
3	IT issues: Central Cardiac Audit Database (used to collect NACR data), other databases, lack of computer, audit issues	17
4	Training (need for, cancellation of, time taken to train up new staff)	14
5	Problems with venues (availability, heating, capacity), facilities, office/clinic spaces	11
6	Patients declining, dropping out, preferences, low commitment, not interested	10
7	NHS/PCT issues (eg Agenda for Change, mergers, job freezes)	9
8	Lack /loss of clerical / admin support	7
9=	Funding / limited resources	6
9=	Time to set up / plan / revisit plans	6
	Other factors mentioned: BHF reporting confusion; transport/geography; workload; reporting; limited capacity; lack of CR options; weather; time of classes;	

	building works; equipment/video not available; difficulties contacting patients (by phone); clinical governance issues; risk assessment issues; poor bid; lack of leadership/staff support; communication; clinical inconsistency; limited service by postcode; no contact; list of colleagues with experience of similar service; parking at hospital (difficult for staff returning from home visits); withdrawal of phase III by an acute trust, other programmes not established in area; local issues/delays; too successful – have had to introduce a waiting list.	

Staffing issues

A large proportion of sites (89%, n=31) reported staffing issues. The main problems were availability of suitably qualified staff, having sufficient cover to continuously provide a service when staff were on leave or off sick, and finding replacements for staff leaving. Some of the other factors listed overlapped with these issues, for example, the need and time taken to train new staff when they had been appointed following someone else leaving; issues with replacing staff because of NHS/PCT changes and funding issues (especially from July 2007 onwards); and workload issues for covering clinical staff were sometimes compounded by a lack of clerical and administrative support. Two sites had found staffing issues were helped by having job-share staff or by pooling staff from CR teams, better enabling staff to cover absences and provide a more continuous service.

Lack of patients

Another barrier reported was a lack of patients, noted by almost two-thirds of sites, where sites were not getting the number of referrals they had anticipated in their bids and/or evaluation aims. This could be a lack of referrals from the acute sector or GPs in the pathway, or because the number of patients requiring and preparing to accept the help that was being offered had been overestimated in making the bids or in setting the evaluation target. Sometimes, it was an actual shortage of patients, but at other times it was due to restrictions imposed by local protocols, the terms of the award on the number of diagnostic groups who could be invited, or being restricted to a limited number of postcode areas. During the project a few sites were allowed to widen their criteria to solve this problem. Finally, one site commented that they had to create a waiting list because its programme had been too successful!

Patients declining or not attending

A related factor identified by some sites (29%, n=10) was that some patients declined or did not attend the programmes they were offered. It was not always clear which types of programmes patients had refused. A few respondents gave specific examples, such as low interest in Road to Recovery, patients going back to work before being offered CR and therefore declining at that point, and patients failing to resume classes after they were cancelled because of hot weather.

IT problems

Around half the sites (49%, n=17) reported problems with IT in general, including using CCAD and having access to computers. Some of these problems were resolved over time. In some cases, this delayed or prevented sites having access to local audit data they required, and in others staff struggled to find time to engage with this aspect of their work. Lack of administrative support was again a related factor here.

Venues

Nearly a third of sites (31%, n=11) reported problems with the availability or suitability of venues. A few of these problems were solved by moving venues. Finally, some sites had under-estimated the time it took to set up the programmes and get them running, resulting in a delayed start.

Planning, transport, lack of coordination

Amongst the barriers, there were a particularly large number of idiosyncratic reasons, some related to details of the original planning of the service. These included: confusion about the purpose of the original bid or a poorly envisaged bid. Sometimes this was because the bid had been written by managers who were remote from the clinical population. Sometimes problems with patient transport and geography had not been foreseen. Poor planning or failure to understand the nature of the task led to: undue workload and limited capacity; clinical governance and risk assessment issues. Other indications of poor leadership or staff support included; poor communication; clinical inconsistency in other practitioners; no contact with colleagues with experience of similar service and infrastructure problems, including building works; necessary equipment not available and parking at hospitals. Finally, problems could relate to difficulties in other parts of the patient pathway, for example, withdrawal of Phase III by an acute trust or other programmes not being established in the area.

Factors mentioned as both a facilitator and a barrier

Some factors were given as both facilitators and obstacles to progress, the most prominent example being the referral and the recruitment of patients. Where the planning had ensured there were sufficient patients and that robust referral systems were in place, the service flourished, and the converse was equally true. Developing effective methods of contacting patients and offering them an appropriate range of options helped to promote increased uptake and reduced the numbers declining or dropping out.

Interestingly, while the qualities of the people making up the CR teams, their enthusiasm, drive, skills and the quality of the relationships they established with partners and patients were cited as the main positive factors, poor progress was rarely blamed on a lack of these qualities. Poor progress was more likely to be blamed on extrinsic factors such as poor leadership and planning from above, a lack of resources (especially sufficient clinical and administrative staff) and infrastructures deficiencies (IT, venues, NHS/PCT changes).

4.3 Profile of selected case study CR programmes

Eight CR programmes were selected as case studies for the qualitative arm of the evaluation, comprising interviews with patients, their carers and staff.

Centres were purposively selected to include four that had made most progress on one or more of its aims and four that had made least progress. Further details of the process of selecting the case study sites are presented in the appendices.

The eight case study sites that were selected according to their performance varied in terms of what kind of CR programmes were potentially available to patients. In some cases, BIG funded new and clearly distinct programmes, such as a home-based CR programme. In others, it funded an extension to an existing programme, for example, a new part of the service targeting particular patient groups or extending the range of community-based CR options provided. In yet others, the funding went towards expanding the staffing of an existing service, providing more of the same, and did not fund a particular aspect of the programme, or target a particular group of patients, that could be identified separately from the existing activity.

The eight case study sites provided a wide variety of services for patients, including:

- education
- exercise classes (at hospital and/or community venues)
- exercise and education classes (at hospital and/or community venues)
- home-based CR
- Road to Recovery
- home visits
- individual walking programmes
- individualised ad hoc programmes.

In seven of the eight sites, the BIG award contributed to extending or increasing the existing range of provision. In the other case, it provided a new and discrete programme of home-based rehabilitation only.

Access to those CR programmes depended on a number of factors. Patients were assessed before being offered CR. Those who were high-risk or complicated cases might be offered particular types of CR or CR at a particular venue which catered for certain patients.

Where patients were offered a choice of programmes, the options offered depended on what was available in the PCT, and the patient's assessed needs. Other factors staff may consider before offering a particular service or venue included: where the patient lived, and if s/he had access to public transport or a spouse/partner who could drive the patient to a class venue. It was not clear to what extent these different issues were considered by staff and used to 'frame' patients' choices of CR programmes and/or venues from those potentially available. However, it was clear from the patient interviews that some were given a choice of type of CR and/or venue, while others were not (see section 5 below).

At the time of selecting the case study sites, half were making good progress towards at least one of their aims, while half were behind. Subsequent analysis of data from later rounds of the rolling survey showed that rates of progress varied over time compared with other sites. Thus, in the final year of the BIG CR programme and at the time of the interviews with patients, carers and staff, the sites were not necessarily doing as well or as poorly as before on each of their aims, compared with other sites. Nevertheless, analysis of the final survey responses shows that the eight case study sites remained diverse in terms of the rates of progress finally achieved with their various aims. Collectively, the eight case study sites had set 14 uptake aims, six of which had scored 50% or better, while eight aims had scored less than 50%. At the final survey point, on the two quality aims specified by these sites, both scored less than 50%.

In order to preserve the anonymity of the eight case study sites they are not identified in this report. We shall refer to them as Sites A, B, C, D, E, F, G and H where we need to distinguish them. In the following sections on the perspectives of patients, their carers and staff, we also do not specify the gender of single interviewees to help preserve the anonymity of participants.

4.4 Summary

There was a good overall response rate to the rolling survey, exceeding 83% at six of the seven rounds carried out. The majority of sites made some progress on their aims. One-quarter of the uptake aims (15/58, 26%) were met or more than met by nine of the 28 sites (32%) that set uptake aims. Forty per cent of the quality aims (4/10) were met or exceeded by three out of seven sites (43%) that had set quality aims. The degrees of under-achievement varied and ranged from narrowly failing to meet their targets through to failing to make any progress at all. Least progress was made by three sites that specified six uptake aims on which they achieved less than 10% of that anticipated, and by one site that specified one quality aim which it did not progress.

Overall, 10 of the 29 sites (34%) included in the analysis met or more than met at least one of their respective uptake and/or quality aims. Conversely, eight of the 29 sites (28%) achieved less than 25% of at least one of their uptake and/or quality targets.

According to respondents, progress was helped by the qualities of the staff in the CR teams and by the working relationships established with partners and patients. The two main factors that hindered progress were staffing issues (reported by respondents from 31/35 sites, 89%) and lack of patients (reported by 22/35 sites, 63%). As most sites experienced these problems, it would seem that these factors alone do not explain why some sites progressed better than others.

5. Patients' perspectives

In the sites selected for the interviews, 301 patients were invited to take part of whom 103 agreed and were interviewed (a 34% response rate). The final sample comprised 70 males (68%) and 33 females (32%). The average age of the full sample was 65.23 years (males = 65.76; females = 64.12). Sixty percent of patients were retired and 34% were working full or part-time. Two patients were unable to work because of their health and four were partly retired or engaged in voluntary work. Forty six percent lived in urban and 36% in rural locations, the remainder living between town and country. Despite our best efforts to invite all eligible ethnic minorities in the seven case study sites to take part in the study, the final sample did not include any non-white patients, and the great majority were British with a few patients from Europe. Further details on the methods used to recruit the sample are provided in the appendices.

5.1 How did patients hear about CR?

Invitations

Patients reported having been given a mixture of written and verbal information about CR, usually while they were in hospital. Some centres also contacted them after discharge to discuss if they wanted to do CR.

In a few cases where patients were initially hospitalised in an out-of-area hospital, patients were given information pertaining to that geographical area as well as contact details for their local CR service, which then supplied more information on the CR provision where the patient lived. In all cases, these patients elected to do CR in their 'home' PCT.

There were also a few patients who initially got information about CR in their local area from their GP, for example, after having been hospitalised abroad and then returning to England, or after having private treatment and then accessing the NHS for CR.

If patients were interested in taking up the offer of CR, they were usually invited to an assessment and then offered a programme, or a choice of programmes. Some patients mentioned that the type(s) of CR they were offered was based on the outcome of their assessment.

Satisfaction with information received about the programme

The vast majority of patients seemed happy with the information they were given on the CR available to them. They thought the information was good and they could not think of any other information they would have liked to have had. However, a few patients were unhappy because they felt the information was too general or not relevant to their situation (for example, being for older rather than younger patients). One patient also felt unsupported in the period between hospital discharge and starting CR with only the local GP to contact for information (and it was felt the GP would only refer the person back to the service).

The main issues with information seemed to arise when patients fell between different hospitals or services, for example, some patients who had been treated in the private sector did not get any information on accessing NHS CR after their operation. Patients who had attended different NHS hospitals noted that they got no information at all (falling between the hospitals they attended), they got duplicated information, or information which was contradictory.

5.2 What choices were patients were offered?

We asked patients if they had been given a choice of what type of CR to do and/or where to do it.

Offers of choice

Overall, 62 patients (60%) reported they had been given a choice of type of programme and/or venue; 41 patients (40%) did not report being given a choice of either, including four patients who claimed they had not been offered any CR at all (of which more below).

Type of programme

Fourteen percent (n=14/103) of patients reported having been offered a choice of *type* of programme. In almost all cases this was between a combined exercise and education group class-based programme, or the Road to Recovery home-based programme, an exercise programme on DVD and home visits to discuss goal setting for behaviour change. These included all nine patients who were interviewed in the site that was funded by BIG, solely to provide a home-based programme and where we only recruited patients who had done this type of programme. The other patients were from three other sites. No patients from the remaining three sites reported having been offered a choice of type of programme. It is not clear if those who were not offered a type of programme was for clinical and/or other reasons. Twelve of the 14 (86%) who were offered this choice decided to do a home-based programme (but it should be reiterated that this includes nine patients from one site where only patients who had done a home-based programme were invited to take part in the study).

Venue

Fifty one percent (n=53/103) reported that they had been offered a choice of *where* to do a class, including patients from all seven sites. The choice was usually between one or more hospital venues and one or more community venues. The majority of patients were offered two options, and the remainder up to five venues. The number of venues patients recalled being offered did not always match the number actually available. This may indicate that staff were offering a selection thought to appeal to or suit individual patients (such as venues that were closer to, or more accessible for, patients), because of other reasons (such as classes at other venues being over-subscribed), or patients may not have always recalled exactly all the venues they were offered (some recalled that a number were mentioned but could not name them all). Of the 53 patients offered a choice of venues for class-based CR, all except four opted to do this type of programme (92%).

No offer of CR

As noted above, four of the 103 patients claimed that they had not really been offered CR at all. Two patients had attended an assessment but were told they were not suitable for CR at that time and that they would be contacted later. One patient was not contacted again. The other was contacted after a two-month delay, by which time the patient had already completed a self-devised programme of walking and returned to work full-time. The patient was disappointed as s/he would have liked to have done a programme to speed up his/her recovery and get back to work more quickly.

Constraints on choice

A few patients reported constraints on the choices they made. For example, three patients from three different sites were told they would have to wait if they wanted to do a class-based programme at their local venue because it was full, or they could choose a non-local venue instead. Three patients who did a home-based CR programme would have been interested in doing a class to be with other people but could not take up this option because they had difficulties with transport, or their shift patterns did not allow them to attend a class regularly.

Satisfaction with choice

Patients were generally happy with the options they had been offered. Looking back on their experience, most could not think of any other options they would have liked to have had, but of course patients may not have been aware of other possible options they were not offered. However, a few patients stated they would have liked to have had more options, for example, of venues that were closer to them, or a different type of CR programme, or a female-only class. One patient, who had been offered a choice of four venues for class-based CR, did not think that was enough options for the size of the city where s/he lived. Another patient, who did a home-based programme, recalled that a class was ‘casually mentioned’ but never followed up or firmly offered and the patient was disappointed that this was not offered as s/he would have been interested in attending a class.

5.3 What kind of CR did patients take part in?

The characteristics of these groups are shown in Table 27. At the time of the interviews, 83 patients had completed a programme and three were still attending; six patients had started but dropped out of a programme; three patients had been offered CR but had declined; and four patients claimed they had not been offered CR. In three cases it was unclear if they had been offered CR and declined it, or not offered it at all; and in one case the patient’s memory was poor and it was not possible to establish many details of his/her CR.

Of the 83 patients who had completed a CR programme, 69% (n=57) were male and 31% (n=26) were female. The majority were aged 50-74 years (80%, n=66) and 13 were aged 75 years or older (16%); the average age was 65.1 years.

Of the three patients (two male and one female) who declined to do CR, all were from one site. They were younger on average when compared to the overall sample (57 v 65 years). They did not appear to be interested in doing formal CR, although one patient followed a programme of exercise suggested by a friend. One of the three had done a CR programme a few years before and did not enjoy it, which seems to have been the reason for declining the current offer of CR.

CR status at time of interviews

As Table 27 shows, 78 patients chose to do a combined exercise and education class-based CR programme, of whom 72 had completed, three were still going and 3 had dropped out at the time of the interviews. Fourteen patients had participated in a home-based programme, of whom all had completed, except for three who had dropped out. Those doing the home-based programmes were older on average (70 years) compared to the overall sample (average 65 years).

Table 27 Patient participation in CR programmes

	Sex		**Age group**			**Lives alone?**		**Type of CR**		**Case study site ID**						
	Male	**Female**	**49-**	**50-74**	**75+**	**No**	**Yes**	**Class-based**	**Home-based**	**B**	**H**	**E**	**G**	**D**	**C**	**F**
Completed N=83 / %	57 69%	26 31%	4 5%	66 80%	13 16%	76 92%	7 8%	72 87%	11 13%	16	6	10	19	3	11	18
Still going N=3	1	2	0	2	1	2	1	3	0	-	-	2	-	-	-	1
Dropped out N=6	3	3	1	3	2	4	2	3	3	2	3	-	-	-	-	1
Declined offer N=3	2	1	1	2	0	3	0	-	-	-	-	-	-	3	-	-
Not offeredN=4	3	1	0	4	0	4	0	-	-	2	-	-	-	1	1	-
Unclear N=3	3	0	0	1	2	3	0	-	-	2	-	-	-	-	1	-
Unknown N=1	1	0	0	1	0	1	0	?	?	-	-	-	-	-	-	1
Sub-total N= %	**70 68%**	**33 32%**	**6 6%**	**79 77%**	**18 17%**	**93 90%**	**10 10%**	**78 76%**	**14 14%**	**22**	**9**	**12**	**19**	**7**	**13**	**21**
Total	**103**		**103 Average age = 65.23**			**103**		**92**		**103**						

Site A were unable to get local agreement to use NACR so we were unable to select any patients to interview and staff only were interviewed.

Completion

The large majority of patients who had completed a programme at the time of the interview had done a class-based CR programme (n=72, 87%) as opposed to a home-based programme (n=11, 13%). The number of patients completing programmes in each of the seven case study sites ranged from three (4%) to 19 (23%). Of the 83 patients who had completed a CR programme, 57 (69%) were male and 26 (31%) were female. The majority were aged 50-74 years (n=66, 80%) and 13 were aged 75 years or older (16%).The average age was 65.1 years.

Reasons for choosing class vs. home-based CR

Those who chose to do a class-based CR programme (n=78) rather than a home based one mainly spoke about why they chose the venue rather than the type of CR. They generally chose the venue because it was 'convenient', 'accessible', or 'closest' to them (mentioned 40 times).In some cases it was a community venue, in others it was a hospital venue that, for example, was on a good bus route. Other reasons given for choosing the venue included references to: the parking being easier; staying with the same staff running the course who they had previously had contact with (each mentioned four times); that they had heard the class was good or that they had confidence in it (mentioned three times). None of the patients who chose a class-based programme intimated that they would have preferred to have done a home-based programme instead.

Of the 14 patients who chose to do a home-based programme, reasons were more often about the necessity than positive choice. For example, patients referred to the inaccessibility of alternative options (mentioned five times), and the fact that they could not drive at the time or had no transport (mentioned three times). Other reasons given included not being able to attend a class regularly because of work or other reasons (mentioned twice), and the cost of travel/parking being a deterrent (mentioned once). The positive appeal of the home-based programmes was mentioned five times. However, three patients mentioned that while they did a home-based programme, they would have been interested in a class if they could have accessed one and/or attended regularly.

Dropping out

Six patients (three male and three female) had dropped out of their CR programmes, three from a class-based programme and three from a home-based programme. The average age of those who dropped out was no different to the whole sample (both averaged 65 years). All except one were retired (n=5) or unable to work because of their health (n=1). Those who dropped out of a class-based programme were from three different sites, while the three who dropped out of a home-based programme were all from one site (where it should be reiterated we only sampled patients who took up this discrete BIG-funded option). In five of these cases (83%), patients had dropped out because they had medical problems and were either advised to stop going or stopped going of their own accord. In the remaining case, the patient had previously done a similar CR programme a few years before, following a previous cardiac event. This patient dropped out half way through a 12 week course (with the agreement of staff), having gone back to work and being reluctant to take unpaid leave for half a day to keep going to the class.

5.4 Patients’ experiences of class-based CR programmes

All eight case study sites offered a group-based programme of exercise and education (although BIG funding did not contribute to this type of CR in one site). All the sites provided these classes at both hospital and community venues. Most patients’ classes were held at venues that were exclusively for CR patients, while some classes were held at venues where members of the general public were also in attendance at the same time. At one site, patients were charged a fee for the class.

What did the group-based classes involve?

As noted, 78 patients choose to do a class-based CR programme from the seven case studies where patients were interviewed. The experiences described below include those who had not completed or who had dropped out of the course, as well as those who had completed it.

The classes included a mix of exercise and education, the latter was optional, but almost all patients attended both components and none did the educational part only. Some patients were advised against the exercise component but it was not clear if they were offered the opportunity to attend only the educational sessions if they wished. A few of these patients indicated that they would have been interested in attending some talks or having contact with people for support.

The length of the programmes varied between six and 12 weeks, with sessions running between one and three times a week. Classes were held in hospitals and community venues, including gyms, leisure centres, clubs and church halls. Classes were held at various times of the day. Each class lasted around two hours. The courses were free of charge, except in one site. The size of classes and numbers attending week by week varied, ranging from as few as two patients to as many as 30. The classes were staffed by a mix of CR nurses, fitness instructors and helpers.

Patients who attended were all at different stages in the class, with some leaving and others joining each week. If patients missed any sessions, for example, because they had hospital appointments or were on holiday, they were usually able to add on the sessions at the end. However, as the educational sessions usually ran in a cycle, patients were not always able to attend the one they missed. Where the courses were under-subscribed, some patients were allowed to continue on beyond the normal length of the course if they wished. A few patients who completed the standard length course commented that they would have liked to have kept going and done a few more sessions.

The exercise component of the course generally consisted of the following:

- arrival and chat in group;
- warm-up;
- monitoring – of blood pressure and heart rate before, during and after exercise. Patients also self-rated the degree of effort involved on a personal record sheet;
- exercise – a circuit around a mix of floor-based stations, with free-weights and in some venues, equipment such as bikes, steppers and rowing machines. Patients may be grouped by fitness level, and exercises individually timed and/or the speed regulated;
- warm-down and relaxation.

After a break, where refreshments were usually provided, there was then a talk by guest speakers and CR staff with different topics each week. A wide range of topics were covered across the case study sites, as shown below.

- The heart/the body
- Treatment/surgery
- Medication
- Resuscitation
- Diet/nutrition
- How to read food labels
- Smoking
- Alcohol
- Lifestyle
- Well-being
- Stress and anxiety
- Feelings
- Relaxation
- Support groups
- Do’s and don’ts
- Having a safe environment at home
- Going on holiday
- Insurance
- Financial assistance / benefits
- Quiz
- Open question and answer session

Where patients were taken to the classes by a spouse or partner, they sometimes stayed and watched the exercise class and participated in the educational part of the sessions.

Views on the classes

Organisation and ambience

In general, the large majority of patients who went to the classes had positive things to say about their overall experience of the course. They enjoyed the classes despite sometimes finding it difficult at first. In particular, they found the staff reassuring; the patients supportive of each other; the talks interesting and informative; thought it was good to have a structure and discipline; liked seeing themselves progress from week to week; and thought it helped build up their confidence. They also liked the social side and making new friends through the group. A few patients thought it would have been boring and difficult following an exercise regime alone.

Group interaction

Patients generally enjoyed doing CR with other people. They found it useful to meet people ‘in the same boat’ (for example, comparing experiences and scars, ‘swapping notes’, and sharing tips and advice), and appreciated having a laugh and enjoying the banter and camaraderie of the group. They also found it useful to meet others who had similar experiences to themselves, others with different heart problems, and seeing that they were ‘lucky’ as there were some people who were ‘worse off’ than themselves. Some patients also found it useful that they could compare their progress (and any issues) over time with that of equivalent others, as if gauging what was normal in their situation. A few patients were uncertain before they started the class that they would enjoy it, as they were ‘shy’ or ‘not a good mixer’, but did enjoy it. However, for one person, being part of a group of patients who had heart problems reminded him/her of his/her situation and raised psychological issues that the person required some help in solving.

A few patients did not really enjoy the course and one did not enjoy the part involving a talk by a psychologist where people discussed their personal problems in a group (the person would have preferred to talk about this in private). Another, who did two classes a week, preferred the class with fewer patients in it.

Venues

On more specific matters, most patients thought that the venue where the class was held was suitable. A few would ideally have liked it to be nearer; one person thought the room could have been bigger; and one found it hard to hear the instructor because of loud music from an adjacent area. A few patients commented that the venue they attended was open to ‘Joe Public’ which one found intimidating at first; however these patients did not have problems accessing the equipment when they needed to. A few patients felt that the quality of the venue was an issue, it being too hot or too cold, or a bit ‘tatty’.

Transport and access

Patients travelled to classes by bus, car, bicycle, walking, and ambulance. Some patients were still unable to drive at the start of the course and had to use public transport or get a lift. Those who drove or were driven generally found it easy and free to park at their venue. However, four patients from one site, all of whom attended a class at a hospital, found it costly and, in one case, difficult, to park. One partner who gave a patient a lift did not stay because of the parking fees, dropping the patient off and returning later to collect the person. No patients we interviewed found the class they attended difficult to get to (although they thought some other people might). A few patients also indicated that the classes were accessible in other ways, for example, in terms of the welcoming ‘atmosphere’ of the class, and their being given paid time off work to attend the class.

Timing of classes

Patients generally felt that the timing of the sessions was fine, although it wasn’t always ideal. Some patients appreciated the fact that the classes were held at times that meant they did not have to travel at peak times. The main groups who struggled with the timing of sessions were those who worked or who had other family commitments. A few people missed sessions at the end of the course because they had gone back to work and did not want to take further (unpaid or sick) leave.

Role of partners

Twenty of the 78 patients (26%) who attended some or all of a class-based CR programme had help from spouses, relatives, friends or other members of the group with their rehabilitation. In most cases, patients were helped in a practical way by being driven to and from one or more of the classes, usually by a spouse. In six cases (8%), spouses also attended one or more of the sessions, waiting during the exercise class and joining in the educational talk. A few patients also acknowledged that they had had help from relatives or friends with other aspects of their CR or during the rehabilitation period, for example, by being helped with heavy lifting, helped emotionally at this time, and by being accompanied on walks because the person sometimes felt dizzy and did not like going out alone.

Individualised programme

The majority of patients who commented on whether or not they felt the CR programme was tailored to their individual needs felt that it was individualised to some extent. Several recognised that the course was a ‘package’ or fairly ‘generic’ but that there was flexibility within that to accommodate the range of patients who attended. Some patients mentioned examples of the ways in which the course had been tailored to their needs: by staff adapting exercises because of an injury or impairment which limited their participation in some types of exercises; by being individually monitored by staff; by being told what to do or not to do; and by being encouraged to go at one’s own pace. A few patients felt that they had been individually ‘controlled’ or held back by staff at first rather than do too much.

Eight patients did not feel that the classes were individualised, and another had reservations about this. Their reasons were that the course: was not strenuous enough or was too gentle for them; that they all did the same general programme; and that the course could not be individualised because everyone had different heart problems. One other patient felt a course was geared to those who were 'at a lower level of physical activity' to him/herself and who had had an MI, whereas this patient had not. S/he wanted to know the impact that more strenuous exercise would have on him/her and felt that staff were 'not interested in sprinting and running' and could not answer his/her questions that were 'outside the box'.

Quality

Finally, patients were asked for their overall views on the quality of the programmes they did, including the staff, venue and organisation of the course. The majority of patients thought that the quality on all these dimensions was good. Some patients were disappointed with some aspects of the programme they did, for example, they felt that the venue was too hot or too cold, a bit 'tatty', a bit small, or one room was not always available. A few would have liked more sessions, and two pointed out they had not been given information about having to pay for the course, or had been given incorrect information about the gym where the class was held being exclusive to CR patients (which it was not).

5.5 Patients' experiences of home-based CR programmes

Five of the eight case study sites provided a home-based CR programme (three providing Road to Recovery); another offered home visits to discuss rehabilitation where appropriate.

As noted earlier, 14 patients chose to do a home-based programme at three of the sites; nine of the patients we interviewed were from one site (where we only sampled patients who had done this discrete BIG-funded programme); four were from a second site; and one patient was from a third site. The experiences described below include those of three patients who started but dropped out of the programme.

What did the home-based CR involve?

At the site which was funded by BIG to provide a home-based programme, the six patients who completed it described a fairly consistent programme, the BHF Road to Recovery, which at this site consisted of the following:

- a home visit, where staff talked to the patient and gave them materials, which included an exercise DVD/video, relaxation CD/video, and written information. Staff might explain and demonstrate and practice the exercises on the DVD with patients, and other exercises too
- patients worked their way through the hour-long exercise programme, between one and three days a week, keeping a record of their pulse and rating how easy/hard they found the activities
- patients worked through four levels of exercises on the DVD, as directed by staff, over several weeks/months
- a nurse phoned periodically to discuss the patient's records; staff might also visit periodically or at completion of the programme
- patients gradually extended their other activities, such as walking
- patients were able to phone staff if they had queries or concerns.

The single patient in another site who was interviewed about a home-based programme described a similar programme to the above, with the addition of receiving information about diet, medication and support groups in the area.

The remaining four patients who received a home-based programme from the third site described CR which seemed to vary more according to individual circumstances. Thus, one patient had started a class but collapsed and was later offered a home-based programme instead, comprising seven or eight sessions of exercise and advice which staff delivered in person. Another patient described a home-based package including advice on diet, help with emotional aspects (at home and through counselling), and progressing from basic exercises through to a DVD (done jointly with staff at first). Another patient was visited and given exercises for the upper body. As s/he got better, s/he was taken for walks outside, given a DVD and four tapes, and the staff sat and talked, visiting one or two times a week for 10 weeks. The remaining patient got a DVD/video which the nurse went through with them and left the patient to do it each day, visiting every two weeks for 10 weeks.

Views on the home-based programme

Adherence and enjoyment

In general, views on the home-based programme were mixed. Some patients thought that it suited them and their lifestyle to do exercises at home, and some found it helpful and enjoyed it. One patient was able to do the exercises despite having other health problems. Conversely, four patients found it difficult to do the exercises because of other health problems. Two patients adapted the exercises, one developing a 10-minute version that s/he could fit in more easily and do more frequently (as opposed to the standard hour-long version which s/he found difficult because of arthritis). Another adapted the exercises because of knee problems. Four patients found the DVD to be 'boring, 'tedious' and 'repetitive'. A few patients found it difficult to fit the exercises into their daily routines, and one felt the exercises did not stretch him/her enough. Finally, a patient did not feel that s/he got the information s/he wanted from staff on his/her prognosis and the implications for his/her lifestyle.

Only one patient found it difficult to do a home-based programme at home: in this case the person worked away from home regularly and had no facilities to play the DVD or time/space to do the exercises when away from home.

Patients reported no issues with the timing of visits and telephone calls, which were convenient.

Convenience, individualisation and support

Patients generally found it easy and convenient to do the programme at home, except one person who worked away from home regularly. The majority of patients who commented on whether or not they felt the programme was tailored to their individual needs, felt that it was. However, two did not and another thought the nurse had tried but failed. Two other patients felt that their other support needs were not recognised. One of these patients felt that s/he was left in ‘mid air’ after having being discharged home without support and being unable to complete a home-based programme. S/he panicked about his/her condition and would have welcomed some reassurance and advice on his/her condition. The other person was left with unanswered questions about his/her health status. One other patient felt that the home-based programme was not individualised, as all patients got the same DVD and book.

Quality

Finally, in commenting on the overall quality of the programme they did, patients were were generally positive about the staff. However, one patient was very disappointed, feeling ‘let down’ by the service and left to his/her own devices. At the time of the interview s/he still felt in need of someone to talk to for ‘reassurance’ and ‘advice on what’s happening’ and ‘how to deal with it’. Another patient felt that s/he was not provided with information s/he wanted, after s/he had previously missed out on this after an unsuccessful consultation where s/he was unable to hear what was said, leaving him/her frustrated.

5.6 How did patients benefit from and value CR?

Patients were asked how they thought they had benefitted from the CR programme. A wide range of benefits were mentioned by patients doing both class and home-based programmes. These are summarised in Table 28 below.

Table 28 Benefits reported by patients

Type of benefit	**Number of times mentioned (patients may have mentioned more than one benefit)**
Psychological/mental health	57
Awareness/knowledge	41
Physical health	23
Overall progress	16
Direction	13
Lifestyle	9
Social	2
Helped partner	1

As table 28 shows, the most frequently related benefit patients felt was psychological, including 26 patients who mentioned that they had gained ‘confidence’ as a result of doing their programme. Patients also referred to feeling ‘reassured’; overcoming their fears and concerns; gaining specifically from meeting other patients and seeing others in a similar situation; and in having an improved mental outlook.

The second most frequently mentioned benefit was how they had gained awareness and knowledge from the programmes and had often acted on this, for example, changing their diet and lifestyle. Third on the list were physical benefits, including improved fitness, strength and stamina. Next was a sense of overall progress with patients feeling, for example, that they were ‘back to normal’, or that doing CR had probably speeded up or enhanced their recovery. Next was the sense of direction that some patients felt they had gained. This included CR pointing them in the ‘right direction’ or ‘path’; giving them a sense of purpose and of ‘moving forward’; and of helping the patients to ‘push’ themselves.

Other types of benefits mentioned included lifestyle, where patients had made changes or where there had been developments, for example, with patients walking more, getting back to work, stopping smoking, and travelling extensively again.

Only one patient said s/he had not gained anything from the home-based programme and another felt that it was too early to say how s/he had benefitted. One person who did a home-based programme felt that s/he had missed out on meeting others at a class.

Many of the patients who did a class-based programme were also invited to carry on with a phase IV exercise programme at the same or a different venue, often run by one of the staff from the phase III programme. When asked if they had carried on with some form of CR, or intended to, the majority of patients reported that they were either carrying on with a formal programme of some kind or carrying on with their CR individually (for example, by attending a gym, or playing golf, or doing more walking).

In a few cases, patients' partners had also taken up a related activity. However, a few patients were not continuing with a programme and did not appear to have made any changes to their activities as a result of the programme. In some cases, this was because of a health problem or injury.

5.7 How did patients think CR could be improved?

Patients were asked if there were any ways that they thought the programmes they did could be improved. Nearly half of those who commented could not think of any improvements (n=45). Where patients suggested one or more improvements, they fell into five main groups listed in Table 29.

Table 29: Areas where patients suggested improvements to CR programmes

Area of improvement	**Number of times mentioned**
More / inclusion of something… (eg information, psychological support, individual tailoring)	22
Logistics (ie access; length and timing of classes)	18
Seamless support (before and after CR)	5
Range of options (exercising/activity choices, venues)	4
Facilities at the venue (tea/coffee, shower, privacy)	2

Things missing or needing more emphasis

The sorts of things patients wanted ‘more of’, or including in the programme, were more education or information on diet and medications. Education should be less repetitive and more tailored to patients, and the information given should also be consistent across all professionals. Some patients also wanted more explanation and practical support around relaxation, psychological issues and coping with depression and anxiety, and more advice and help with claiming benefits. A few wanted more strenuous exercise regimes and sophisticated equipment. Some patients thought the Road to Recovery DVD could be less repetitive and boring.

Logistics

Patients suggested more accessible venues, that the length of class-based CR programmes could be made more flexible – shorter or longer depending on individual need, that the timing of classes could be more flexible (especially for people who have gone back to work and who work shifts), more local venues, more sessions (especially if the programme was a six week one), and courses to be available throughout the year (and not just school terms).

Seamless support

A few patients pointed out gaps in support in the period immediately *after* hospital discharge and *before* their CR programme started (the time between discharge and starting a CR programme in the seven case study sites appeared to vary from around three weeks post-discharge upwards), and in follow-up *after* their CR programme ended. For example, one patient thought the three or four weeks s/he waited without contact did not help with the person's emotional issues at this time. One patient thought that it would be useful to have some exercises to do before starting a class. After doing a CR programme, one patient would have liked the opportunity to do a further CR programme, and another would have liked to have had a medical follow-up (where the patient observed s/he could get feedback and also the service could observe patients' outcomes and learn from this).

Range of options

A few patients would have preferred more options over what CR exercise/physical activities to do for example: options to include swimming; a bigger choice of venues, and who with, such as meeting patients who had been through the same thing, and limiting access to rooms where classes were held to CR patients only.

Facilities

Finally, two patients suggested improvements to facilities – one thought it would have been nice to have tea or coffee available (and was willing to pay), the other wanted a quieter area for the class and to be on their own (and not with the public also present). Another wanted to be able to shower so as not to have to sit through the educational session feeling uncomfortably sweaty after the exercise component.

5.8 Summary

A total of 103 patients were interviewed from seven of the eight case study sites (a response rate of 34%). The patient sample was diverse in terms of age and sex, but lacked any ethnic minorities (the few identified on NACR were invited but none responded positively).

Eighty six patients had completed a programme or were still going, six had started a programme but dropped out, three had been offered CR but declined, four said they had not been offered CR (contrary to what was recorded on NACR), and in four cases their CR status was unclear.

The majority of the patients interviewed (66%) had been given a choice of class or home-based programme and/or venue of class, and most were happy with the options that they were offered. Seventy eight patients had chosen to do a combined exercise and education class-based programme and 14 patients had chosen a home-based programme. Those who did a class-based programme chose a venue that was convenient and closest to where they lived. Those who did a home-based programme had difficulties accessing other options and/or preferred this option. The large majority of patients who attended the classes were very positive about them. They particularly liked meeting other people ‘in the same boat’ as them. Patients who did a home-based programme were more ambivalent about their experience. Of the six patients who dropped out, half started a class and half a home-based programme. Five of the six dropped out because of medical problems.

The main benefits patients reported of their CR was building their confidence and to raising their awareness and knowledge of their condition and how to manage it.

Patients generally found it hard to see how the programmes they did could be improved upon. Where they did make suggestions, it was usually to do ‘more of’ some aspect of the programme or to improve the access and flexibility of the programmes.

6. Carers' perspectives

In the interviews with patients, they were asked if they had help from a relative or friend with their CR. We consequently identified 19 carers who we invited to take part in a short telephone interview, 15 of whom initially responded positively. Eventually a final sample of 11 took part (a 58% response rate). We refer to these informants using the term 'carers' as a generic term, to describe the unpaid assistance provided by these relatives during patients' CR.

The 11 carers were linked to patients in five of the seven case study sites where patients were recruited and interviewed, ranging from one to four patients per site. Ten of the 11 patients had attended and completed a combined exercise and education class-based CR programme, one had done a home-based programme. Ten of the 11 carers were spouses, and one was a close relative. Six of the carers were male and five were female. The average age of the carers was 66.3 years, ranging from 56 to 80. Nine of the carers were retired and two were not working at the time of the interviews (although one was working at the time of the patient's CR). All were white and British/English.

6.1 How were carers involved in CR?

The carers we interviewed were involved in patients' CR in various ways.

Practical and motivational support

Of the sample whose carers were interviewed, nine out of 10 patients were helped by being driven to and from the venue by a carer (in one case this was a 40 mile round trip). Five of the carers mentioned joining the educational part of the class, and one was allowed to join in the exercise class after checking with his/her GP. A few carers also mentioned that they had played a role in patients' rehabilitation by helping to motivate them to do a class, and by helping with some activities of daily living (heavy lifting, housework, gardening, cooking) while the patient was unable to do them. A few carers also felt that they had helped to watch and monitor patients' progress, for example, seeing if they were doing too much or too little.

Generally, the carers we interviewed did not find it difficult to help patients in the above ways, although a few did report having to take unpaid time off work, or having to cancel social engagements to drive patients to CR, and paying for petrol and parking. A few had found it difficult to park at the hospital venues, or found it hard helping at times because of their own health problems.

Benefits of the carers' involvement

Several carers reported that they saw how the patients' progressed over time and that this helped put their minds at rest. A few felt they understood the issues patients' experienced better through having attended the talks and that there were other advantages to being there, for example, being able to take on board dietary advice they were given, being able to discuss things together while they were 'fresh', and helping where the patient was unable to hear all that was said because of a hearing impairment. Some carers also thought that their involvement had specifically helped the patients' attendance and/or recovery.

6.2 Issues identified and changes requested by carers

Co-participation of carers

Seven of the 11 carers interviewed (64 %) said that they would have liked to have been more involved in the classes, while another (who was not a spouse) did not think his/her relative would have wanted him/her there. Three would have liked to join in the exercise part of the class, and one the education part.

The reasons carers were given for not being allowed to do the exercise were various – lack of places in the class, health and safety, and insurance. Two carers from one site had not been told or had not realized they could stay at the class and attend the education part, and both would have been interested in this. The one person who was allowed to join in requested this him/herself and had to get the approval of his/her GP.

The suggestion that carers be allowed to join in appeared to relate to carers' desire to better support the patients rather than directly for their own benefit (although one patient thought it was a waste of time sitting and waiting).

Assessment of carers' needs

Only one carer reported any attempt to assess their needs separate from those of patients, saying that staff had talked to him/her about how s/he felt and how s/he had been affected by his/her partner's condition and that this talk happened privately, while the patient was exercising.

Inclusion of carers' perspectives

Carers also suggested other changes that would enable CR to be more inclusive of carers' perspectives and directly benefit them, including being able to talk to staff in private; being given information directly from staff (rather than always hearing through the patient); and having a meeting/talk which was about the role of carers and effects on them of supporting their partners/relatives through CR. As noted earlier, none of the educational sessions specifically included this topic.

6.3 Summary

A total of 11 carers were interviewed from seven of the eight case study sites (a response rate of 58%). The sample was small but many of the patients we interviewed did not have help from a relative or friend with their CR or did not consider the help they had to be significant or notable enough to be followed up by the researchers.

Carers mainly helped patients by driving them to and from the CR classes, which some also sat in on, and most did not find this too difficult. They felt they benefitted from being involved by seeing patients' progress and, where they attended the educational part of the sessions, by better understanding the patients' situation. Some carers would have liked to have been more involved in the exercise and/or educational sessions. It was suggested that an educational session devoted to carers could be added (which none of the case study sites appeared to offer among the otherwise wide range of subjects covered).

7. Staff perspectives

A total of 12 professionals were interviewed from six case study sites (six leads and six staff) with between one and three leads and/or staff interviewed per site. Non-lead staff included a mix of CR nurses and others involved in the delivery of the programmes to patients, and managers from PCT and acute trusts. All had been involved with the programmes for at least a year, including five who had been involved in preparing the bids. The majority worked part-time on the BIG CR Programmes. Seven of the staff interviewed were, or had been, wholly or partly dependent on BIG funding.

In order to protect the anonymity of those who took part, details that could identify them have been omitted. Further details of the methods used to collect and analyse data from the staff interviews are in the appendices.

7.1 Achievements of the programmes

Before asking the staff for their views on the achievements of the programmes, the interviewer checked if there had been any major changes in the aims of the projects as stated in their original bids and/or evaluation aims. One site had, soon after being awarded BIG funding, dropped its plans to offer Road to Recovery partly because of what they learned was required to offer it (which the bid had not included) and partly because it was felt to be too exercise-based. This was agreed with the BHF and the bid was revised. The other main change, by three other sites, was to original staffing plans. These changed in different ways: by the work and role of the staff brought in to work on BIG CR Programme being shared with members of the wider CR team (partly due to external changes in the way MI patients were diagnosed, meaning that staff roles would overlap anyway, and also so the programme was not reliant on individual staff delivering it); and by appointing staff from different backgrounds or at different grades to those originally planned because of difficulties recruiting and/or initial appointments not working out as planned. The achievements that staff talked about therefore related to these *revised* programme aims and configurations, as well as to the *original* aims they specified.

Overall success

The staff were all generally very positive about their programmes and did not identify any major failings. The main areas where three sites thought they had failed to achieve were, firstly, not having reached as many hard-to-reach patients as they would have liked (especially women) and, secondly, not having as much uptake as they had anticipated of new home-based programmes, including Road to Recovery. Staff at one site observed that patients needed to be highly motivated and confident to do Road to Recovery at home alone, albeit supported by phone calls and visits. As noted earlier, one site also acknowledged that it had not introduced Road to Recovery as originally planned, because of the resources required and doubts over its suitability for some patients. Other areas where staff felt they had not achieved what they set out to do were: improving uptake generally, using NACR and improving the quality of the service as quickly as intended owing to appointing the wrong type of staff.

Meeting the aims

The staff all thought that the six programmes they were involved with were successful, except for part of one programme where Road to Recovery was not introduced as originally planned. One lead thought that they had done what they set out to do, and achieved a little bit more. Only two staff from one site qualified their remarks by adding that their particular way of providing a home based programme was a ‘very expensive success’ and that there was still ‘room for improvement’.

Improvements in quality

The main achievements of the programmes, referred to by staff from all six case study sites represented, was the provision of an *enhanced* service compared to what was available before. Thus, patients had more choice of types of programmes, and where and when to attend. They also had access to a wider range of professionals, such as physiotherapists, trainers, and psychologists, who added to the skills of existing teams. Two staff from one site also thought that staff knowledge within the team had been enhanced by the training that the new BIG post-holder was able to facilitate. Staff from three sites thought that the work done by staff in the programmes had led to more 'joined up' services across organizations, to a more standardized and equitable service across an area, and to an improved patient journey through the phases of CR. Staff from another centre felt that good levels of retention had been achieved as patients moved from Phase III to Phase IV.

An unanticipated benefit of the programmes noted in four sites was that, by offering more choice of programmes for patients, those electing to do the new ones had freed up capacity in existing hospital-based programmes, for higher-risk patients (who would be less likely to be offered the new options), and for patients doing classes (as some were now choosing to do the new home-based Road to Recovery option). As a result, there was no longer a waiting list at one centre.

Improvements in uptake

While no reference was made to any dramatic improvements to the total number of patients attending, staff from all six sites thought that more of the hard-to-reach patients were coming, especially the elderly, those in rural areas, those with complex needs, those with no transport, as well as some with mental health problems. Also mentioned were the younger/fitter patients who worked, and those from geographical catchment areas previously not covered. Many of these were patients who it was thought would not have previously taken up CR. Staff from one site felt that rates of DNA (did not attend) had been reduced.

7.2 Issues encountered by staff

In the course of the interviews staff described issues they had encountered which are summarized below.

Bids

Staff from three sites acknowledged that there were some problems with their initial bids. For example, they did not ask for administrative support, travel expenses were under-estimated, the aims were unrealistic/over-optimistic or the bid was ‘rushed’ and poor. Staff from one site also thought that the information they had regarding Road to Recovery, on which the bid was based, was poor, and staff from another felt that the BIG/BHF brief for the patient groups they were allowed to target was overly restrictive.

Staffing

Reference has already been made to changes in staff roles or grades of appointments that some sites made as their projects evolved over time. Other staffing issues were also mentioned, which echoed those mentioned by respondents to the rolling survey. These included not having adequate administrative support, struggling to cover staff absences, lack of managerial support, and problems appointing staff. Two new issues were also identified, namely: getting the ratio of staff roles right; and issues about managing multi-disciplinary staff who are employed by different organizations or departments, especially with regard to invoicing (from a manager’s perspective) and communication with and support of staff on the ground (from CR staff perspectives).

PCT changes

Staff from four sites had experienced issues with the PCT-based leads for their projects changing and/or with PCT mergers and reorganisations. PCTs in two sites were currently reviewing the CR service, and in one of these sites the question of how funding of the programme was to be continued was still open. Where CR services already had a single service covering the PCTs, impact of reorganisation seemed relatively limited compared to areas where there were different CR services covering different PCT patches and/or PCTs.

NACR

Staff from five of the six sites included in the analysis referred to a wide range of issues with using NACR. Because of being awarded BIG funding, efforts had been made to enable these sites to use NACR in order to help with the evaluation of the programmes. Some of the sites had therefore been using NACR for up to three years, as the system was being piloted and rolled out. Various problems were reported, including: transferring data across different systems (some trusts wanted to maintain their own existing databases as well as move to NACR); the database being un-user-friendly; the forms being long and fields open to interpretation; questions not being relevant; the database not reflecting the range of input of CR from acute to community care/across all phases; difficulties retrieving the data for local audit purposes (and so having to keep separate records for this); being offered help with NACR that did not materialize; providing feedback but this being slow to be acted on; and having to buy extra licenses. In two sites where NACR appeared to be working well, staff found it useful and others supported it, recognizing they needed the information to show the benefits of CR. A recent survey of all current users of

NACR has confirmed that other programmes experienced similar initial problems but that in the majority of cases these have been resolved.

Reporting and the evaluation

Finally, a few staff had related issues with the amount of reporting required by the BHF and for this evaluation. To them, at times, this seemed excessive and onerous.

7.3 What helped and what hindered achievements?

Staff from the case study sites confirmed many of the factors that had been identified in the analysis of the rolling survey as having helped them to achieve what they did.

Staff qualities

The qualities of the staff were again referred to. Having good, well motivated, multi-disciplinary staff teams; staff with appropriate backgrounds; and low staff turnover was a great help. So too, was having the support of managers and steering groups. Several staff identified particular ways of working that had helped. These included: sharing BIG work out amongst team members, thereby allowing staff to cover absences; sharing the skill base; ensuring the service was not reliant on one person; team working; good communication; having good links with local services; and promoting the service locally. Staff from three sites also indicated that, during the time of the BIG CR Programmes, the CR services had been boosted by additional PCT funding and drives, or by provision of additional administrative support.

Support

More generally, in commenting on the roles of different groups involved in the programmes, staff in all sites found the BHF to be supportive, some adding that this was needed more in the early days of the programmes and less as time went on. One site found the BHF to be flexible over the changes it made, while another did not find the BHF responsive to its proposed solution to a change of lead for the programme. All the sites had project Steering Groups which staff from all sites except one found helpful. The exception was due to the lack of PCT interest in, and active support of , the BIG initiative.

Staffing issues

Again, staff identified similar factors inhibiting progress as those reported by all the programmes in the rolling survey. The major problems related to staffing issues and included: delays in appointing staff; appointments of unsuitable staff; lack of team work; and lack of cover. Lack of support from managers and the CR team, lack of administrative support, and ways of working (such as poor communication, and how PCTs operate) were also reported.

Obstacles

More evidence was found of unanticipated setbacks affecting progress, such as: having to find alternative venues sooner than expected; patients not having DVD or video-players or knowing how to use them (Road to Recovery depends on this); and delays in related services affecting referrals. Some staff also mentioned limitations on what they could do or achieve given the limited range of venues available, lack of flexible times for sessions, and lack of capacity to increase the number of sessions.

One issue that was identified in the rolling survey that was only mildly evident in these interviews, was referrals. Some of the staff who were interviewed implied that there had been a few problems, but that these had been addressed and thus did not appear to have been major issues for the sites concerned.

External drivers

Finally, some external changes were also referred to by staff, such as the introduction of Agenda for Change, job freezes by PCTs during the time of the projects, and the national change in the diagnosis of MI patients (which led to the expansion of, and changes to, CR provision in one site).

7.4 Looking back and moving forward

Looking back on how things had gone, staff were asked if they would do anything differently.

Changes to the application

Staff from three sites said they would stick to their original plans. Others would do a few things differently such as: ask for a bigger budget; request more administrative support; change the balance of staff; include a wider range of cardiac condition groups than was specified; build in cover for staff; include a second venue; ensure patients did not have to pay; send NACR data using Lotus Notes (rather than importing via another system); and manage the programme from within the CR service (not the PCT).

Improvements

The improvements staff suggested followed on from the above. They included: offering more choice of venues, for example, developing a non-gym-based class for aerobics/dance that might appeal more to women; increasing choice and capacity of community and home-based packages, including finding alternatives to Road to Recovery; increasing staffing and multi-disciplinary elements, such as input from psychologists; providing cover for physiotherapists (from equivalently skilled staff); and developing better ways of evaluating outcomes, including improving NACR.

Sustainability

The BIG/BHF grants were made for three years, and on applying, the PCTs undertook to continue funding after that period. At the time of the interviews, five of the six sites had funding agreed from PCTs to continue and in the remaining site funding was agreed, although exactly how it was to be used and distributed was not decided. Hence there was still uncertainty over whether the programme would continue as it was (and staff noted it had taken a lot of work to secure this funding). Staff reported one of the sites had plans to expand its service, adding the Heart Manual and Angio Plan to what it provided. Staff from another site felt that its sustainability had been helped by embedding the programme within the overall work of the CR team as the programme evolved.

7.5 Summary

A total of 12 staff from six of the case study sites were interviewed, including six leads and a mix of professionals involved in providing and/or managing the programmes. All the staff interviewed felt that the programmes had been a success, except for one aim that was not achieved by one site. Collectively, the main achievement reported was of an enhanced service being provided to patients, reaching more hard-to-reach patients, especially the elderly, those in rural areas, those with complex needs, and those with no transport. Staff also suggested that patients were benefitting from access to a more multi-disciplinary service, including physiotherapy and psychology, in some sites. However, staff did not feel they had reached as many hard-to-reach patients as they would have liked, especially women, nor increased uptake of new home-based programmes as much as they would have liked. Some staff thought that offering different types of venues/classes such as non-gym/dance/aerobics might appeal more to women, and that alternative home-based programmes to Road to Recovery need to be developed for some patients for whom this is not suitable or appealing.

Staff views on the issues encountered during the programmes, and what had helped and hindered progress, confirmed the views expressed by respondents to the wider rolling survey of programmes.

Finally, staff reported that funding at five of the six sites had been agreed with PCTs to continue the programmes, and the remaining site had some funding agreed but the distribution of the funds was still uncertain.

8. Discussion and synthesis

This section brings together the findings of the three components of the evaluation that have been described above, to determine how well the BIG CR Programme met its aims.

There were two main aims, to bring the benefits of CR to people who otherwise would not be able to access it (through a lack of provision or because they were in a 'hard to reach' demographic group) and to improve the quality of the CR experience for patients. Uptake and quality are not mutually exclusive, a single action could help to achieve both, for example, using the funding to offer a home-based rehabilitation programme may lead to greater patient choice (a quality gain) or for a patient with no transport the only opportunity to take part (an uptake gain). Despite this, we believe it is possible to answer questions about both aims individually.

8.1 Did the BIG CR Programme improve access to CR?

In analysing the initial applications and in helping programmes choose their 'main' aims, it became clear that the great majority chose to concentrate on improving uptake. This seems eminently sensible from a utilitarian perspective because increasing the current 40% uptake to that recommended in the National Service framework for CHD of 85% can be predicted to save many lives, and, it could be argued, may have been the most effective use of the additional funding.

It is absolutely clear that the project succeeded in increasing the number of people who took part in CR. In the three years of the project more than 10,000 patients were treated, the majority of whom would be unlikely to have had this help without the BIG CR Programme. More than half of the programmes depended almost entirely on BIG funding and in the great majority of cases where programmes existed prior to the BIG CR programme, they would not have had sufficient staff to treat all of the additional patients.

The full impact will only be evident in the future because almost all the programmes have been adopted by the NHS. During the project, some programmes grew the initial funding by attracting further NHS support and others have plans to do so. It seems inevitable that over the coming years many more tens of thousands of patients will be helped. From this one impact alone the BIG CR Programme can clearly be judged to be a success.

8.2 How did the programme increase access?

One of the reasons for the poor uptake nationally is simply that there are insufficient opportunities to take part. In a survey conducted by the Healthcare Commission, 60% of patients said they had not attended cardiac rehabilitation because they had not been offered it.[5] This is usually because there are insufficient staff to recruit and treat patients which BIG funding addressed by increasing provision, new staff and working in primary care recruiting through new pathways, with new venues. It was clear from the surveys and the interviews with staff that many had to seek out patients and to develop new ways to access patients. It is most likely that the additional patients were able to access CR because there was more of it on offer and more healthcare staff actively seeking to recruit them.

Interviews with staff suggested other ways in which uptake had been improved, offering a home-based programme and targeting hard to reach patients were the most commonly mentioned. However, for the reasons given below it seems that these factors were not a significant driver of uptake.

8.3 Did the BIG CR Programme improve access to CR for disadvantaged groups?

Although in making their applications many of those applying mentioned reaching hard to access patients as one of the potential benefits, once the main aims had been elicited for the purposes of our survey it became clear that few of the centres were specifically set up to reach these groups. Not surprisingly then, when we consider the whole of the BIG CR Programme, the patient demographic was almost identical to that of the other 200 programmes in the NACR database. Any slight differences were either statistically non-significant or too small to be of importance. The one large and statistically significant difference was that, taken as a whole, the BIG patients were *less* likely to include those from non white-British ethnic groups. It seems most likely that this was an artefact caused by the fact that many of the programmes were rural or in areas with few non white-British patients.

Some projects did have a specific goal to target certain groups, where there were more than three programmes targeting the same demographic group we combined their results. The groups were those targeting: older people; non-white British patients; women and those in employment. When we compared these programmes against the UK 'average' for their specific aim, only two were statistically different from the UK average. The programmes targeting ethnic minorities had a greater percentage of non-white British participants than the other UK programmes, in particular people from the Indian sub-continent. This finding depended almost entirely on the contribution of one of the four programmes which specifically set out to recruit Asian women to dietary classes.

Disappointingly, the four programmes targeting women had a slightly *lower* percentage of female patients. Although this latter difference was only around 4% it was statistically significant and consistent across all three years of the project. The ratio of men to women attending all programmes was around two to one respectively. This is roughly the same ratio as the incidence of heart disease between genders, and the idea that women are less likely to attend than men may reflect a previous era in development of rehabilitation. In the 1960s and 70s CR was commonly *only* offered to *men* below retirement age and was strongly biased towards exercise training and building physical strength to speed return to work. It may be that this discrimination has largely disappeared and that women are no longer disadvantaged. Obviously the recruitment rate for both sexes could be much better, but the failure-to-recruit appears to be approximately equal across genders.

Interviews with the staff running the BIG CR programmes revealed a more complex answer. Some staff specifically reported having found it difficult to enrol people from the underrepresented groups, women in particular. Others felt that the addition of BIG funding *had* helped them become more successful in helping those people who might not otherwise have attended the programme. These included people in rural locations for whom more local facilities had been put in place. The quantitative data does not support this impression, because people in the BIG CR Programmes were no less likely to give distance or transport problems as a reason for not attending and the overall use of home-based programmes across the whole programme was low.

Staff mentioned having some success recruiting people from hard to reach groups who needed more individual help or encouragement to attend, for example people with mental health problems. An improvement in recruitment of people with individual health needs, or those who needed more time and encouragement to attend, would not have shown up in the demographic data collected by NACR. Other NACR data (reported below) confirms that recruitment success in BIG CR programmes *was* better than usual and on this point the staff impressions may well be correct.

It appears that, with the very worthwhile exception of those few programmes that specifically set out to recruit more patients from ethnic minorities, examples that could be copied more widely, the BIG CR Programme did not lead to a change in the demography of those attending CR.

8.4 Did the BIG CR Programme improve the quality of CR provision?

There were a number of measures that indicated that the quality of the BIG CR Programmes was better than the other CR programmes in the NACR database. The most important were

- much shorter waiting lists
- BIG CR Programmes had much lower refusal rates
- BIG CR Programmes had much better completion rates

Part of the reason why wait times were shorter may have been because the programmes were in primary care, and when they started had no backlog of patients. Indeed, initially some struggled to get referrals, but this does not account for the fact that in both the BIG and the other CR programmes waiting times decreased markedly over the three years of the programme, with the BIG CR Programmes still being significantly better in the third year of the assessment. Short wait times are of great benefit to patients. Most MI patients are back to work in six weeks and this commonly prevents many from being able to attend CR or leads to premature drop-out.

As noted above, the main reason why patients do not attend is that they are not invited, but for those who are invited, the main reason for not taking part is that the patient declines to attend. Interestingly, between 2006-07, in BIG CR Programmes, refusal fell from 45% to 33%, whilst in the other programmes of the UK it stayed stable at about 32%. This may have been because, as some centres believed: the wrong staff had been employed initially; over time BIG staff became better at encouraging people to take part; or because as time went on they were offering more attractive or flexible delivery of their programmes.

8.5 How did the BIG CR Programme lead to better quality?

The main measure of quality we used was comparing the BIG CR Programmes against the measures collected by the NACR for all of the other CR programmes of the UK. This measure is therefore restricted to those aspects of the NACR that measure quality, and differences are relative to the current ‘norm’ rather than an ‘ideal’ target.

The success of CR depends on helping patients assess and change those behaviours that lead to poor health, and it is reasonable to suppose therefore that quality depends in large part on the calibre and the enthusiasm of the staff. We have no clear evidence as to how the observed relative improvements in quality described above came about, but two possibilities suggest themselves. Firstly, it may be that the people who succeeded in gaining BIG BHF funding were more motivated or designed better programmes than the majority of the UKs CR programmes. Although the new appointees were to be based in primary care, a number of the successful applications were driven by established hospital or community-based CR teams who were already particularly motivated to improve current standards.

Secondly, due to recruitment problems, there may have been a much higher staff to patient ratio than most programmes and this may have resulted in staff having more time for each patient and in their putting more effort into attracting and retaining patients. All three of the main improvements, waiting time, recruitment and retention of patients, could be accounted for in this way and it may explain why the costs (a function of staff time vs. patients treated) were around £50 higher in the BIG CR Programmes. The great majority of CR Programmes in the UK are significantly underfunded and if this hypothesis is correct it suggests that significant improvements in these aspects of quality would flow from increasing funding per patient to all CR programmes.

The secondary measure of quality was patient experience and satisfaction with the programme as gathered in the interviews. The satisfaction levels were generally high and only a few of the 101 patients who had been offered CR and were interviewed had any explicit criticisms (these have been described in section seven above). The interviews reveal that 60% of the patients were offered a choice of venue and/or method (home versus class-based CR), an aspect of quality improvement that a number of programmes had stressed and one that is currently highlighted in the BHFs Campaign for CR. Of those interviewed 14% had been offered a choice of home or class-based programmes and 51% of venue.

8.6 Did the BIG CR programme help patients achieve improved health or psychological outcomes?

The quantitative data indicates that the health gains made in the BIG CR programmes were, in almost all respects, equal to those from other programmes. The greatest improvements were in the number of people compliant with recommended weekly physical activity levels, a reduction in smoking and improved psychological status. Health related quality of life improved, particularly for physical fitness, daily activities, dependence on others and social life. As with all other CR programmes these outcomes are far from perfect and even with a 20% improvement only around half of the people taking part met the prescribed activity levels, and the mean body mass index actually increased a little. There was no clear evidence that the medical and social outcomes were better for BIG CR programmes than achieved in the other CR programmes in the NACR dataset.

8.7 How well did individual programmes meet their stated aims?

Each programme was asked to give one or more aim, and we worked with them to quantify these so that a percentage of success could be worked out for each aim over the three years. Clearly this method was far from perfect and the deficiencies are discussed in the section on methods in the technical appendix. It was partly necessitated because, even after a formal textual analysis of the successful applications, it was far from clear what would define a successful outcome for any individual programme. Some programmes set multiple goals, some only one. A few programmes over-achieved on most of their targets, and a few achieved very little of what they had aimed to do, even if they had only set a single target. Only 11 programmes met or exceeded at least one of the uptake or quality targets they had set. It would appear that the majority of programmes had greatly over-estimated what they would achieve. This was despite having the chance to refine the promises made in the bid, receiving a clear explanation from us that it would be best to set realistic targets, and assurances that the individual targets and outcomes would not be passed on to the BHF or BIG.

Despite the fact that most had significantly under-achieved on one or more of their stated aims, and apart from some caveats, the interview sites were all very positive about their programmes and unable to identify any major failing. Only one of these sites was a completely new programme, which may have biased the response, but the majority felt that the main benefit of the programme was a general enhancement of their existing programme, additions to the existing resource that improved the quality through greater multi-disciplinary skills, extending patient choice or enabling a satellite site to operate. They generally made no claim to having reached disadvantaged groups, but reported that through reorganisation and the use of home-based programmes, they had often managed to free up existing programmes to see more high risk patients in the hospital programmes and in one case entirely abolish the waiting list.

It is clear, that across the life of the project, from the submission of the application onwards, there was a general reduction in aspiration. Many of the applications promised far more than the targets agreed after the awards had been made, and there was a similar reduction of aspiration between setting the targets and the eventual achievements of the programmes that staff expressed satisfaction with. It is not clear if this was a case of optimism being defeated by the realities of the health service, or if it was the result of a degree of gamesmanship.

In considering how much programmes achieved, it also has to be borne in mind that for many of the programmes the amount awarded was just sufficient to cover the salary of an additional junior member of staff, or part time help from a more highly qualified health professional. For some of the applicants interviewed the award represented a small and relatively unsecure addition to the existing budget.

8.8 What helped and hindered programmes in achieving their aims?

This question has been covered in depth in section seven above. To summarise, the facilitators of success were: a realistic proposal fully endorsed and agreed by the local health economy with clear lines of responsibility and patient flows; following through after the award with good local networks; a local steering group and support from clinicians and managers. In the staff interviews these factors were all mentioned but the most commonly mentioned facilitator of success was the enthusiasm, drive and professionalism of the staff employed on the programmes.

The main obstacles faced were: a poorly thought out application; constant change in the NHS organisations that were involved in the bid; staff turnover; lack of cover for illness, maternity and holidays; problems in referrals and tensions between rehabilitation staff working in hospital settings and the newly funded BIG centres in primary care, and, to a lesser extent, around multidisciplinary working. It should be noted that this evaluation took place over a period of unprecedented change within primary care, with PCTs being merged and a substantial economic crisis in many. Staffing problems were often compounded by job freezes, reorganisation and mergers.

In the early days, many of the projects were surprised by the lack of patients, and the failure to recruit was the main reason why they failed to meet the targets they had set. The staff in a number of centres found that they had to spend a lot of time developing relationships with others in the wider local health service to find patients, in particular with existing secondary care programmes, and that one of the most important facilitators of success was developing robust referral protocols and building a relationship with other clinicians so that they would refer on patients.

A number of programmes had planned to use the BHF Road to Recovery home-based exercise programme but had no experience of using it and found difficulties in implementation and in getting patients to accept it. Feedback from patients indicated that they too were equivocal as to its benefits. As a result relatively few patients actually used this programme.

Whilst there is no doubt that the staff faced many external challenges in just the way that they described, there appeared to be only a weak relationship between the number or type of problems encountered and the actual performance of programmes. As performance against the targets showed some programmes performed relatively poorly in all aims and others performed well in most of their aims, this suggested that one of the most important predictors of success was the ability and determination of the individuals involved to solve problems whenever they arose.

9. Recommendation

Recommendations

The award process

In future programmes, applicants should be asked to state, in objectively measurable terms (numerical where possible), one or more aims for their project. This would lead to more realistic aims and simplify the evaluation process.

Problems often arose after the award because the bid had been prepared with insufficient consultation with others in the patient pathway. Applicants could be asked to specify the referral pathway and produce written evidence that they have consulted with, and have a protocol in place, with significant others in that pathway.

Cardiac rehabilitation

Some of the patients expressed the need for further psychological support, and evidence from the NACR dataset showed that few, if any, CR programmes had a psychologist available to them. Steps should be taken to meet the minimum staffing levels specified in the British Association of Cardiac Rehabilitation guidelines, and to offer psychological support to those who require it.

The programme significantly reduced wait times, but some patients still felt unsupported after discharge and before the CR programme started. CR programmes should work to ensure that CR begins from discharge.

Some patients felt cut off from support after the programme finished, and might have benefitted from the introduction to patient support groups, or for those wishing to continue with exercise classes, to community based exercise opportunities.

Although some centres offered a choice of venues and/or the alternative of home based rehabilitation, in reality there was only one viable choice for some patients, particularly those disadvantaged by distance or infirmity. Other research has shown that the patients' decision to choose a home or hospital based programme was not dependent on distance alone but may be preferred for other reasons. Rehabilitation programmes should continue to develop choices of method and location, and make these available to all patients, not just those who otherwise could not attend a hospital/group based programme.

The improvements we observed in quality were most likely the result of the additional funding making more staff time available to patients. The BIG programmes were on average better funded than the other CR programmes in the UK, suggesting that these too would benefit and deliver real improvements if they had greater resources. Those funding CR should establish if the programme meets the recommendations contained in the NICE purchasing Guideline for CR, and provide additional resources if it does not.

Relatives and carers should be more involved in CR programmes, in particular having an opportunity to: join classes, both educational and exercise; to speak to staff privately and have information given to them directly.

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Appendices

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A. Methods

The methods of the three components of the assessment and the details of how each was conducted are described below.

1. Overview

The evaluation used three main methods: analysis of data from the National Audit of Cardiac Rehabilitation (NACR); a rolling questionnaire survey of the 36 individual CR programmes in which quantitative data on progress towards individual, self-defined, goals was collected and qualitative data on factors helping and hindering progress were also collected; and finally a more detailed examination of eight case study programmes was carried out in which qualitative data from interviews with patients, carers and staff from the purposively selected centres was collected and analysed. In this section we describe the methods used in more depth.

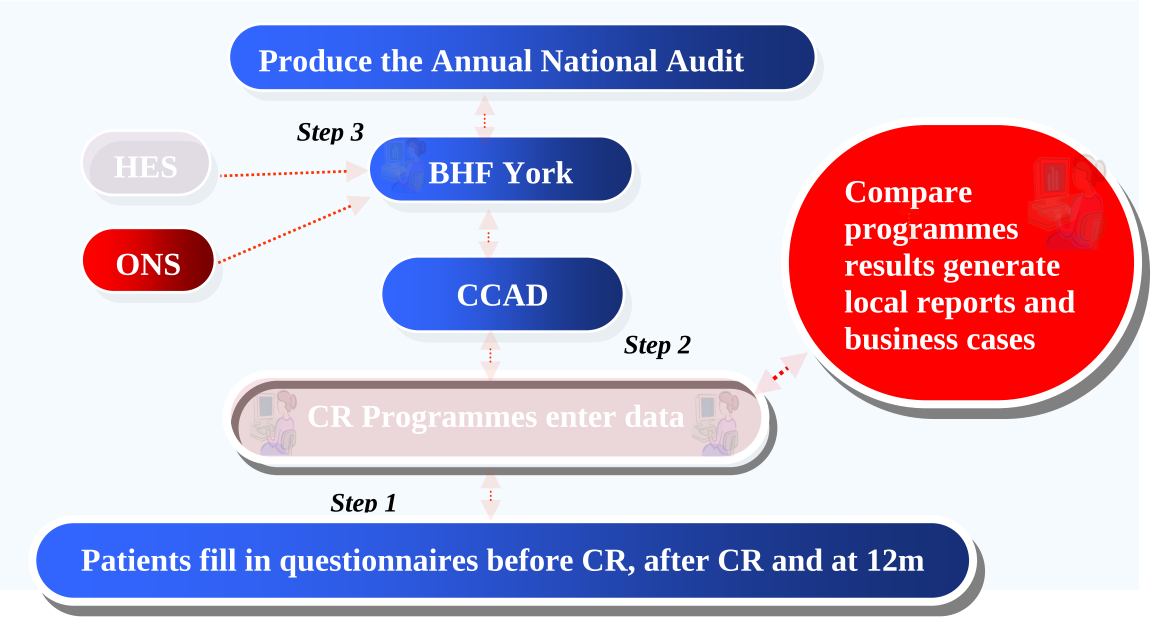
2. NACR

The National Audit of Cardiac Rehabilitation (NACR) is a collaboration between the BHF, the British Association for Cardiac Rehabilitation (BACR) and many of the CR programmes in the UK to collect data about their programmes so they can improve services for patients. The diagram below represents the process.

Step1. Patients complete the minimum dataset questionnaires three times: before they start their rehabilitation, after the rehabilitation programme, and 12 months later. The CR programme staff score the questionnaires and add some data of their own and then enter it either into a Lotus Notes database, or via the web. Staff can also download data to analyse themselves to create local reports or business cases.

Step 2. Data are automatically uploaded to the Central Cardiac Audit Database (CCAD) servers using the NHS network. CCAD shows the data to the programme with benchmarks added, which shows how well the programme is doing compared to all the others in NACR. They also take off any personal identification (name, address etc) and then make it available to the York NACR Team for further analysis.

Step 3. The York team take the NACR data and combine it with other sources of information, such as the Department of Health's Hospital Episode Statistics, to write reports.



All the CR programmes were sent the NACR software in June 2005 (with the exception of one programme which had not started then but which was subsequently sent the software). It was anticipated that it would take a year for all CR programmes to have installed the NACR software and begin to send data. Some of the CR programmes were slow to install the database, the most common reason being that NHS Trust IT departments were tardy in installing the Lotus software and opening the firewalls to allow for online connection. Some sites had a number of staffing issues which meant there was either a delay in entering data, or the data of some patients who had benefitted from BIG funding were not recorded on NACR at all. As a result of these problems, analysis of these quantitative data was delayed.

The BHF four regional Heart Health Coordinators (formerly known as Cardiac Rehabilitation Coordinators or CRCs) provided support and advice to all the sites and, during the evaluation, contacted those sites that were not sending data. This was very successful and by the time of the evaluation's second annual report, 33 of the 36 programmes were sending data; three centres had only just recruited staff and had not installed the software.

2.1 Analysis of NACR data

The NACR dataset includes process and outcome data, including health gain and health related quality of life as well as social data such as employment status. This information is collected upon starting the programme, after 12 weeks, and after 12 months (by post). These data were used to profile the patients who attended the CR programmes and to examine the outcomes achieved. They were also used to further examine issues arising from the findings of the other quantitative and qualitative data analysis for the present evaluation.

3. The rolling survey of CR programmes

A rolling survey of the 36 CR programmes over the three years of their funding was carried out at three or six monthly intervals in order to examine progress towards the individualised aims of each programme, and the barriers and facilitators of success. At the start of the study, up to three main aims were agreed with programme leads for the purpose of the evaluation. Leads were told that aims had to be measureable, and could relate to uptake or to quality improvements that they were seeking to make with BIG funding. The bespoke survey was then sent at intervals to project leads (or their nominated staff) initially by email and by post, and thereafter by whatever method respondents' preferred (usually email). Two reminders were normally sent, rising to four for the last round of the survey, where appropriate.

At each survey point, respondents were asked to complete a statement for each aim, providing a numerical indication of their progress towards the final goal, for example that 100 of the hoped for 600 patients had completed a home-based programme. They were also asked to indicate if they were ‘on target’, ‘ahead of target’ or ‘behind target’ for each aim, and to comment on what had helped and hindered their progress to date (see Appendix D for an example of the questionnaire).

Seven rounds of the survey were carried over the three years of the evaluation, between January 2006 and January 2008, involving 35 of the 36 CR programmes (one was very late to start and so was excluded from all rounds of the survey). Two additional rounds were originally planned, but one was omitted in order to coordinate the survey with the BHFs own reporting requirements, and the other was skipped in order to reduce the amount of reporting for sites.

3.1 Response rates to the rolling survey

There was a good response to the seven rounds of the rolling survey: overall a response rate of 85% was achieved. Response rates to the individual rounds of the survey ranged between 66% and 94% (see Table N).

Table N: Response rates to the rolling survey, by round (n=35 sites).

Survey round	% response rate
1	83
2	94
3	94
4	89
5	omitted
6	86
7	66
8	omitted
9	86
Overall	***85***

Seventeen sites fully co-operated, with 100% returns. However, three sites only responded to three or fewer of the seven survey rounds. At the final round, when overall progress towards sites stated aims was analysed, 30 of the 35 sites responded, a response rate of 86%. Collectively, these 30 sites originally specified a total of 74 aims (64 relating to uptake and 10 relating to quality). Six aims were excluded from the final analysis because the data were problematic, or because the aim had been terminated from the programme at some point. The final analysis was therefore of 68 aims stated by 29 sites (58 aims relating to uptake by 28 sites, and 10 aims relating to quality by seven sites). These quantitative data were examined to assess to what extent sites had met their individually defined targets as they approached the end of their three years of BIG funding. Then qualitative data from all 35 sites that took part in the survey and each round of the survey (where they responded) were examined to identify the factors that respondents indicated had helped and hindered their progress over time.

3.2 Analysis of survey data

At each round of the survey, statistical data on progress achieved, and qualitative data on the factors that had helped or hindered progress, were extracted to individual programme-level charts summarising the results over the seven rounds for each site. Statistical data were also transferred to a grid showing all the sites' progress towards their aims over time. Aims were also classified according to whether they related to 'uptake' or 'quality' improvements, and these scores were separately monitored. Where sites had stated multiple targets within a single aim, these were split into individual, measureable, targets. Thus sites were measured on up to six aims each.

At the third and final survey rounds, carried out around July 2006, when 23/36 programmes had been running for a year or more, the percentage progress to each target was calculated. The results at round three were used to select the eight case study sites. The results obtained at the final round were used to assess the extent to which sites had met their individualised aims as defined for the evaluation.

Qualitative data on factors that helped and hindered progress were examined separately. These data were extracted into summary charts, and types of factors were identified. References to these factors over the three years of the programmes, and across the programmes, were examined in order to establish which factors were common and which unique to the 35 programmes involved, and which played a part in the beginning, middle and end of programmes. Initial analysis of these data also helped to inform the design of the topic guide used in the staff interviews.

While every effort was made to design the survey so that individualised outcomes could be measured, and so that it was as easy to complete as possible, some problems were still encountered with the survey. Programme leads were asked to define aims that were measureable and realistic. However, in some cases, they proved to be immeasurable. For example, one site defined a target relating to the numbers of patients who took up individual walking programmes – but it transpired that these self-referrals were not recorded so it proved impossible to say how many patients took up this option. Whether sites set realistic goals - both in their original bid and subsequently in their stated aims for the evaluation - is not clear, but some appear to have been very ambitious. Some sites also failed to start on time, mainly owing to staffing problems, and hence this delay meant that they had not been running for as long as other sites when we assessed site progress towards their targets at the third survey point. In addition, by the time of the final survey close to the end of the BIG CR programme, some staff had moved on and/or programmes were in transition and several reminders had to be issued to obtain the good response rate we achieved.

Finally, the researchers had to make several checks with respondents to query some of the figures supplied because of inconsistencies in how the data were reported (sometimes quarterly and not overall cumulative figures were provided). Several sites were unhappy at having to provide data on a quarterly basis to the BHF for grant monitoring purposes as well as separate, cumulative, data on a rolling basis to the researchers on their individualised aims for purposes of the independent evaluation. The researchers responded by reducing the planned number of surveys from nine to seven rounds, and by synchronising the timing of the surveys with the BHF. This may have helped overall cooperation with the survey, but not necessarily confusion over the need for the two lots of data to be submitted regularly to both BHF and the independent evaluation. However, it should be noted that sites were made aware in applying for funding that, if successful, they would be expected to take part in an independent BIG-funded evaluation.

4. The case studies

Eight CR programmes were selected for more detailed evaluation, comprising four that had made most progress towards one of their targets and four that had made least progress. Interviews with staff, patients and carers were to be carried out in all sites. However, one site was unable to help with recruiting patients and carers because of problems with using the NACR database that were not resolved within the evaluation timetable. As a result, only staff were interviewed in this site. The main purpose of the interviews was to identify and explore the factors that helped and/or hindered progress, from both staff and user perspectives, and to investigate their experiences of the programmes. Qualitative data from this work was examined in conjunction with statistical data from other aspects of the evaluation.

4.1 Selection of the case study programmes

Using quantitative data obtained from the first three rounds of the email survey, we calculated the progress each programme had made towards achieving each of its aims by July 2006. For example, if a programme aimed to increase uptake to 360 patients after three years and had achieved 50 patients at round three of the survey, it would have achieved a score of 14%. The results relating to uptake aims and quality aims were recorded separately. Where data was missing at round three (two programmes), these aims were excluded. Where PCTs had been awarded funds late (two programmes), they were also excluded.

Each programme's *best* achieved score for uptake and/or for quality aims was then recorded and ranked. The ranked results were divided into tertiles and mapped onto a two-dimensional chart showing results for both best uptake and/or best quality scores. As more programmes had specified uptake rather than quality aims, more of the former appeared in each tertile. Likewise, each of the programme's *worst* score for uptake and/or quality was recorded, ranked and charted as above. All the scores and ranking were independently checked by two researchers.

The eight case study sites were purposively selected to ensure that the final sample was diverse in terms of making most/least progress towards uptake targets and progress towards quality targets at round three of the survey. In addition, of those programmes that appeared in the 'most' and 'least' progressive tertiles, those which included one or more aims which targeted 'hard-to-reach' groups were selected (regardless of which aim the score related to, as once selected, the site's progress on all it's aims would be explored in-depth as part of the case study work). Finally, a check was made to ensure that the final selection of sites was geographically diverse.

As the majority of the programme's aims related to uptake rather than quality, it was decided that the final sample would include six based on uptake and two on quality.

The short-list of programmes was given to the BHF Cardiac Rehabilitation Coordinators (CRCs) at the Steering Group meeting in November 2006, without identifying whether sites were from the groups that had made most or least progress in relation to one of their aims. CRCs were asked if there were any major practical or logistical reasons why any of the short-listed programmes should not be included as a case study site. It was at this stage that one programme was found to be 'suspended' and hence it was de-selected and replaced with a reserve that had already been identified.

4.2 Recruitment of patients

As the seven sites provided a mix of BIG and NHS-funded CR programmes, where possible we sampled patients who were clearly identified on NACR as having been offered a BIG-linked programme (NACR includes a BIG or ‘BIG’ tag to identify such patients). However, where the funding benefitted the entire service, the sample population we drew from included all eligible patients in the sites concerned.

Assuming a continuing average rate of 133 patients per month over the five months available to recruit patients, a potential study population of 665 patients was estimated from which to recruit a target of 160 patients, ideally 20 per site, over the period March-July 2007. For logistical reasons, it was decided to send sites a maximum of 30 invitation packs to forward to patients over two rounds of recruitment (each round comprising an initial letter of invitation, followed by a reminder letter 2-3 weeks later). It was thought that this would help the sites to manage the workload involved over just two rounds (with the option of a third round if necessary) It would also enable the researchers to monitor responses and target certain patients groups if necessary according to the following purposive sampling strategy.

Efforts were made to ensure the sample included up to 20 patients per site where possible and including the following: a mix of patients who attended a programme and who declined to attend; patients aged below 75 and 75 and over; ethnic minorities; and a minimum of 30% female patients. It was hoped that this mix would enable patients from relatively ‘hard-to-reach’ groups (such as ethnic minorities, older people and women - all of whom the BIG CR programme intended to reach more) to be included in the overall sample, to examine how their views on the BIG CR programme compared with those of other groups.

The patients selected at the first recruitment round were therefore drawn as follows:

- All patients selected from sites where the total number of eligible patients was 30 or less
- All ethnic minorities (where known - not all sites were able to provide these data)
- All non-starters (where known - not all sites were able to provide these data)
- All people aged 75 and older
- The remainder of the sample was made up of an equal mix of male and female patients, drawn randomly from the remaining sites which had more than 30 eligible patients.

Anonymised information on patients recorded as having been invited to take part in the BIG-funded CR programmes in the case study sites were extracted from the NACR database by the researchers.

Data were extracted on all patients who should have completed the programme within the previous six months so that the interviews could focus on those with relatively recent experience of the programmes. Patients who were recorded as having been invited but declined to attend over the same period were also included, except for the following that were excluded because the reason given for non-attendance was that they had died, they were having ongoing investigation, or they had mental incapacity. Patients who were listed as not having taken part because they were 'too ill' were not automatically excluded by the researchers, instead, sites were advised to further exclude any patients whom they judged it would be inappropriate to send invitations to, to take part in the research because they were known to be very ill (but not, for example, because they were very frail) or for other difficult or special circumstances (for example, they were known to have been recently bereaved).

There were two periods of sampling, the first in August 2007 for patients who should have completed a CR programme in March or April, and the second between October and December 2007 for patients who should have completed in May or June. One of the sites was unable to identify from NACR which patients had benefited from BIG funding, and had to provide the anonymised patient information from a local database to the researchers for sampling. They were unable to provide the information needed for the second sample to be drawn within the timeframe of the study and subsequently only one sampling round was conducted at this site. As previously noted, one site did not have records in a usable format and no patients were sampled from this programme. Details of the population approached, response rates and final sample achieved are presented in section 6.2.1.

NHS sites were then informed which patients had been selected and sent invitation packs to address and post to the sample. The invitation packs included an information sheet for patients about the study, a covering letter, and a response form and pre-paid envelope to return to the researchers if they were interested in taking part in a telephone interview. If there was no response within two weeks, the sites were requested to send out one reminder packet. Upon receiving a reply indicating they were potentially interested in taking part in the study, the researchers then phoned respondents, using the contact details they had provided, to discuss their possible participation in the study and answer any questions they had. If patients decided they did want to take part, a provisional appointment for a telephone interview was made. The researchers then wrote to the respondent, confirming the appointment and enclosing a consent form to be completed, signed and returned in the pre-paid envelope provided before the interview, along with a summary of the topics to be discussed in the interview.

At the agreed time, the researcher telephoned the patient and conducted a semi-structured interview lasting around 35 minutes. Patients were asked about their basic demographic details (age, living and work situation), and the heart condition that led them to be referred to cardiac rehabilitation. If the patient indicated they had accepted to offer of rehabilitation they were asked a series of questions pertaining to the programme (choices, views on access and organisation, what they had achieved, and suggestions for improvement). If they indicated they were not offered rehabilitation, or refused an offer, this was briefly checked and discussed as appropriate.

Responses were noted on paper by the researcher during the interview. Patients were asked their consent for the interview to be audio-recorded for the researcher's reference. Immediately after the interview, the researchers checked and clarified their notes and where necessary, the recording was played back to clarify or add to the contemporaneous handwritten notes. The interviewing researcher later typed up the notes in abbreviated format onto a pre-coded pro-forma, for subsequent input and analysis using MAXqda software for analysing qualitative data. The interviews were carried out by three of the researchers (JH, SP and CP).

After the interviews, patients were sent a thank you letter from the interviewing researcher, and a copy of their consent form. The letter included details of where they could access a report of the work on-line when published.

4.3 Recruitment of carers

In the interviews, patients were asked if they had help from relative or friend with their CR. Where patients described having help, they were reminded that as part of the evaluation we were interested in interviewing a sample of 'carers' about their role in patients' CR and we asked for the patients' permission to contact them if they were selected for this sample. They were sent an invitation pack for carers, comprised of an information sheet for carers, a covering letter, and response form with a pre-paid envelope. No reminder letters were sent to carers, owing to time constraints for the study. The same protocol as for patients was then followed to set up interviews with carers who responded positively. One carer asked to respond in writing because of hearing problems.

In this case a document following the topic guide was prepared and posted to the carer.

Carer interviews were scheduled for approximately 15 minutes. In the semi-structured interviews, they were asked for basic demographic information, and then a series of questions about the nature of helping, participation in the CR programme, feelings about helping, problems incurred and suggestions for change. The same researcher who interviewed the patients carried out the related interviews with carers (JH and SP). After the interviews, carers were also sent a thank you letter from the interviewing researcher, and a copy of their consent form.

Data from the interviews with carers were processed in the same way as for patients, except that due to the small number of such participants and shorter length of the interviews, notes of the interviews were coded and analysed by hand.

4.4 Recruitment of staff

Staff views on their experiences of setting up and delivering the programmes, and the outcomes of them, were also sought in the eight case study sites. Up to four key staff who had been involved with the programme for at least a year were to be interviewed, including the project leads where possible. In February/March 2008, one of the researchers contacted the leads to invite them to take part in an interview, and to identify other key staff to approach. By this point, some key staff had left post, limiting the number of staff potentially available to interview.

The leads were asked to identify and provide contact details for up to three other staff involved with the BIG CR programme, either directly providing rehabilitation or at a managerial level. A maximum of four staff in varying roles were selected in cases where more than four were identified. Leads and staff were then approached via email or telephone to inform them of the study and an information sheet provided. Those wishing to be interviewed returned a consent form and a mutually agreeable date and time for the interview was set. Interviews took about 45 minutes and staff were asked for their consent to the interview being audio-recorded. The semi-structured interview covered the following topics; type and length of role, changes made since submission of the bid, progress achieved, the impact of the funding on access, uptake, quality, hard-to-reach goals, unanticipated impacts, factors that helped and hindered the programme, future plans, and how they would have done things differently.

Interviews with staff were audio-recorded and transcribed. In two cases, the transcripts were supplemented by notes where the recording was partly damaged.

After the interviews, staff were sent a thank you letter, and a copy of their consent form. They were informed that a hard copy would be sent to all BIG programmes in due course and told where they could access a report of the work on-line when it was published.

Copies of the key study documents used in the work with patients, carers and staff are presented later in the appendices.

4.5 Description of patient sample

A total of 321 eligible patients were identified across the seven case study sites for the four month period March-June 2007. Sites did not send packs to 20 patients, for reasons of being deceased, frailty or unable to contact them. Of the 301 packets that were sent, 113 patients initially registered an interest in taking part. Interviews with 10 patients were not pursued or conducted due to the following reasons; problems scheduling the interview (n=8), interest was withdrawn (n=1), and patient reported never having had a cardiac event or offered rehabilitation (n=1).

A total of 103 patients were interviewed for the study, from 301 invited, a 34% response rate. The final sample comprised 70 males (68%) and 33 females (32%). The average age of the full sample was 65.23 years (males = 65.76; females = 64.12).] The sample included six patients aged <50, 79 patients aged 50-74, and 18 patients aged 75 or older.

Two patients were identified on NACR as not having accepted the offer of CR, however during the interviews it emerged that seven patients either did not take up the offer or claimed to have not been offered CR at all.

The majority of the patients interviewed (n=62, 60%) had fully retired. A third (n=35, 34%) were working full or part-time. Two patients were not employed and unable to work because of their health (2%). The remaining four patients were partly retired/partly working or engaged in voluntary work (4%). The sample of interviewees included a good mix of patients living in urban areas (n=47, 46%), rural areas (n=37, 36%), and in-between locations (n=19, 18%). The sample did not include any non-white patients and the vast majority were English/British, although a few patients were White/European. (Note: In this report, the term ‘a few’ refers to fewer than five individuals; we also do not refer to the gender of single individuals to help preserve the anonymity of participants).

We achieved our aim of a minimum of 30% women in the sample and managed to interview a sizable proportion (n=18, 17%) of patients aged 75 and over. However despite sampling all the patients recorded on NACR as ethnic minorities and others of unrecorded ethnicity (n=42) all our interviewees were white. This could be a reflection of low diversity within the sites we selected as case studies (and we did not factor this into the selection process), or due in part to inequity of access to CR for the non-white population. Because we selected our sample from a CR register we had no means to identify patients who were not assessed for CR, thus we would not capture patients excluded due to language or other barriers.

4.6 Description of carer sample

In the interviews with patients, they were asked if they had help from relative or friend with their CR. Where patients described having help, they were reminded that as part of the evaluation we were interested in interviewing a sample of ‘carers’ about their role in patients’ CR and we asked for the patients’ permission to contact them if they were selected for this sample.

We consequently identified 19 carers who we invited to take part in a short telephone interview, 15 of whom initially responded positively. Eventually a final sample of 11 were interviewed (a 58% response rate), with the remainder unable to be contacted within the timeframe for these interviews. One carer took part by completing a written version of the topic guide, at his/her request. We refer to these informants using the term ‘carers’ as a generic term, to describe the unpaid assistance provided by these relatives during patients’ CR.

The 11 carers were linked to patients in five of the seven case study sites where patients were recruited and interviewed, ranging from one to four patients per site. Ten of the 11 patients had attended and completed a combined exercise and education class-based CR programme and one had done a home-based programme. Ten of the 11 carers were spouses, and one was a close relative. Six of the carers were male and five were female. The average age of the carers was 66.3 years, ranging from 56 to 80. Nine of the carers were retired and two were not working at the time of the interviews (although one was working at the time of the patient’s CR). All were white and British/English.

4.7 Description of staff sample

Leads from all eight case study sites were contacted by phone and/or by email to invite them to take part in an interview, and to identify other key staff to approach. All eight sites initially responded identifying a total count of 30 professional staff (including themselves). A maximum of four staff in varying roles were selected in cases where more than four were put forward at any one site. Despite reminders, leads from two sites did not provide contact information for their staff and did not schedule interviews for themselves. Out of the 19 professionals directly contacted (eight leads and 11 staff), 16 expressed an interest in being interviewed (six leads and 10 staff) but four staff over three sites did not return the consent form.

A total of 12 professionals were interviewed from six case study sites (six leads and six staff) with between one and three leads and/or staff interviewed per site. Non-lead staff included a mix of CR nurses and others involved in the delivery of the programmes to patients, and managers from PCT and acute trusts. All had been involved with the programmes for at least a year, including five who had been involved in preparing the bids. The majority worked part-time on the BIG programmes. Seven of the staff interviewed were, or had been, wholly or partly dependent on BIG funding.

4.8 Analysis of qualitative data

Once all the patient interviews were processed in the above way, the files were then imported into MAXqda for analysis. As the uploaded files were all pre-coded, an index was automatically generated by the software which facilitated retrieval of the data according to predefined topics. These included: information patients received about CR; choices patients were offered over type of CR and venue; patients’ experiences of CR; whether or not patients had help from a carer with their CR; patients’ overall views on their CR programme; and any recommendations as to how CR could be improved. In addition, information on patients' demographic and CR characteristics were added, using MAXqda's 'attributes', to facilitate analysis by different patient groups and sites where appropriate. For example, analysis of patients' experiences of CR looked for any variations in views across patients who had completed a programme versus those who had started and then dropped out of a programme, and for differences in experiences by type of CR (class-based CR versus home-based CR programme) and across the case-study sites. This analysis was carried out by retrieving data by topic and relevant attributes. The retrieved data were then read and an index of each participant's comments made. A summary of the main themes or categories arising from this analysis was then compiled. For example, the reasons why patients dropped out of a home-based CR programme were listed and compared with the reasons of those who dropped out of a class-based CR programme.

Analysis of data from the carer interviews was carried out by hand. Charts were developed to summarise their views on key topics. Analysis focused on the role played by carers in patient's rehabilitation, their views on their involvement, and improvements they suggested for carers and/or patients benefit.

The staff interviews were also analysed by hand. These transcripts were read and charts developed to summarise their views on key topics, and to compare views across sites and by staff roles. This enabled individual staff perspectives at different sites to be compared on topics such as: whether the programmes had changed over time; whether the project had been a success or not; what had been achieved and what not; the roles of groups involved in the programmes; issues they had to deal with; and views on the sustainability of the programmes. Analysis of the staff interviews was also supplemented by documentary analysis of available quarterly reports submitted by the case studies to the BHF. Findings of this analysis were examined alongside results of analysis of the quantitative and qualitative data from the rolling survey.

4.9 Discussion of methods

Methodological challenges and issues

The evaluation sought to examine the success of the BIG CR programme to:

1. increase the uptake of CR services, particularly among groups of people who currently make low use of existing services.
2. drive sustainable improvements in the quality of services on offer to patients.

These two these aims are complimentary and sometimes difficult to separate, for example, widening the appeal to recruit a wider range of patients and thereby increase uptake usually also means improving the quality of a service. Despite this caveat, whenever possible, we categorised each project's aims as either, mainly aimed at increasing uptake, or, mainly aimed at improving the quality of a service.

The diversity in the aims and methods meant that 'success' had to be measured at the individual centre level and then concatenated to provide an overall index of success for the whole project. We were keen to capture what 'success' would mean in a project's own terms but we also wanted to make this comparable across centres, and as objective as possible. We wanted to examine the relationship between 'success' and various facilitators and barriers to achieving success. This meant we had to develop a continuous measure that would allow us to rank outcome in a continuum between success and failure. Finally, we also wanted to sample progress with achieving the aims across time, so we needed a measure that could be asked repeatedly that would give us a percentage of the aim achieved each time we took the measurement.

Many of the applications stated multiple aspirations. Few had defined their aims in concrete or numerical ways. We felt that as in most cases, the funding would provide only one additional part time worker it was unrealistic to expect multiple improvements across a range of outcomes. Centres had not been told they would be assessed on delivering the benefits they claimed in the application.

Therefore, we allowed each centre to choose between one and three ‘most important’ aims from their application and worked with them to have these stated in a way that could be objectively measured.

The great majority of centres were able to use the questionnaire as intended but a few had problems. For example, in some cases it became obvious that the measures agreed with the programme lead turned out not to be useful because the data was not available. For example, one site defined success with a target as the numbers of patients who took up an individual walking programme – but it transpired later that these self-referrals were not recorded by anyone.

A problem across the evaluation was that some sites failed to start on time, indeed some took up to 12 months after the award to become fully operational, which meant that they had not been running for as long as other sites when we assessed how well all the sites were progressing.

Another problem was staff mobility, especially towards the end of the assessment when it was not clear if the post would be maintained. New staff required a lot of help with the method and often multiple reminders were required.

Other problems included discontent from staff in some centres because the BHF also required them to report progress but using different time periods and collecting slightly different activity figures.

Allowing sites to define their own aims was both a strength and a limitation of the survey. In theory this allowed sites to set individual, bespoke, targets against which their progress could be measured. However, while we asked sites to set aims that were both measurable and realistic, in some cases targets did not prove to be measurable, and in others they appear to have been unrealistic, usually over-estimating beneficiaries and occasionally setting what were arguably modest targets. Using such relative measures of success means that the results could reflect poor target settings as well as actual progress. Targets may have been poorly defined partly in an effort to secure the BIG funding and partly because of the poor baseline evidence on which to estimate how many more patients would benefit from are agree to come to a new programme.

The case studies

The method is well tried and understood and few problems arose. One of the sites chosen was unable to help with recruiting patients and carers because of problems with using the NACR database that were not resolved within the evaluation timetable. As a result, only staff were interviewed in this site. In some centres, by the time the staff interviews were conducted some of the key staff had left the post, limiting the number of staff potentially available to interview.

Lack of ethnic minorities in patient/carer interview sample:

We hope that further research into the possibility of inequitable access will illuminate the situation, however until that time we feel that the lack of diversity in our sample is problematic and the findings should be interpreted with caution when considering the CR experience of ethnic minorities.

On use of NACR

All the CR programmes were sent the NACR software in June 2005 (with the exception of one programme which had not started then but which was subsequently sent the software). It was anticipated that it would take a year for all CR programmes to have installed the NACR software and begin to send data. Some of the CR programmes were slow to install the database, the most common reason being that NHS Trust IT departments were tardy in installing the Lotus software and opening the firewalls to allow for online connection. Some sites had a number of staffing issues which meant that there was either a delay in entering data or that the data of some patients who had benefitted from BIG funding were not recorded on NACR at all.

B. Research Governance approvals

On 16 November 2006, the Central Office for Research Ethics Committees (COREC) advised that the case study phase of the evaluation was considered to be ‘service evaluation’ and hence did not need ethical approval from an NHS research ethics committee. The University of York’s ethics committee chairman also advised that the study did not need its approval. Under the terms of the research governance framework for health and social care research, this part of the evaluation did still require research governance approval from the PCTs involved. The Research and Development (R&D) Departments for the eight PCTs, and one umbrella R&D organisation in the North West of England, were all approached for advice on their local requirements for this evaluation. For some R&D departments, the fact that the evaluation did not require formal ethical approval meant that there was no clear protocol for granting approval and this had to be negotiated at length. One R&D department had no procedure for dealing with this type of evaluation and an individual had to be identified by the local CR staff to review the proposal and give approval on behalf of the PCT. In another PCT, the case study work was simply approved by a relevant manager without having to go through a formal R&D process.

All the necessary documentation was prepared and submitted for approval to all of the eight case study sites early in May 2007. Where R&D Departments did not have a clear formal protocol for granting approval for evaluations such as this, getting approval took time to negotiate, slightly delaying this phase of the research.

In order to obtain research governance approval for the case study phase of the evaluation, a number of documents for the interviews with patients, carers and professionals were prepared and submitted as part of the applications for approval. These included a summary of the project and a recruitment flowchart as well as the following documents for those to be interviewed:

- Invitation letter for patients/carers/professionals from researchers

- Appointment letter (sent with consent form) for patients/carers/professionals
- Information Sheet for patients/carers/professionals
- Response Form for patients/carers/professionals
- Consent Form for patients/carers/professionals
- Summary telephone interview topic guide for patients/carers/professionals
- Thank you letter (sent with copy of consent form) for patients/carers/ professionals

It was agreed by the evaluation steering group that the topic guide for the interviews would be piloted within one or more of the case study sites where research governance approval was to be obtained (rather than in a separate site where an additional application might have had to be made).

C. Evaluation timetable

Tasks 2005 - 2006	Jy	Au	Se	Oc	No	De	Ja	Fe	Ma	Ap	Ma	Ju
Programme Description Matrix	▨	▨										
Identify goals & define criteria for success	▨	▨										
Design email questionnaire				▨								
Email survey							1st			2nd		
Email survey analysis of success, facilitators/barriers & relay to Matrix											▨	
Design links with quantitative data				▨								
Start on MREC application												▨
Local research team mtg			▨			▨			▨			▨
National Steering Group mtg 1												▨
Annual report 1												▨

Tasks 2006 - 2007	Jy	Au	Se	Oc	No	De	Ja	Fe	Ma	Ap	Ma	Ju
Email survey	3rd			4th			5th			6th		
Email survey analysis of success, facilitators/barriers & relay to Matrix											▨	
Define index score of success – 3 groups = highly, moderately and least successful	▨											
Develop interview schedules, information & consent docs	▨											
Identify 2 pilot sites		▨										
LREC application for pilot work		▨	▨									
Pilot work 2 sites				▨	▨							
Select 8 case studies from most & least successful groups				▨	▨							
MREC application for 8 case studies								▨	▨	▨	▨	▨
R&D application for 8 case studies								▨	▨	▨	▨	▨
HC application if needed for 8 case studies								▨	▨	▨	▨	▨
Links w quantitative data				▨								
Local research team mtg			▨			▨			▨			▨
National Steering Group mtg 2												▨
Annual report 2												▨

Tasks 2007 - 2008	**Jy**	**Au**	**Se**	**Oc**	**No**	**De**	**Ja**	**Fe**	**Ma**	**Ap**	**Ma**	**Ju**
Email survey	7th			8th			9th					
Email survey analysis of success, facilitators/barriers & relay to Matrix											▨	
Case study interviews with patients & carers	▨	▨	▨	▨	▨							
Case study interviews with staff	▨	▨	▨	▨	▨							
Case study qualitative data analysis				▨	▨	▨	▨					
Links w quantitative data							▨	▨				
Local research team mtg			▨			▨			▨			▨
National Steering Group mtg 3												▨
Final report									▨	▨	▨	▨
Dissemination											▨	▨

D. Research documentation

D1. Study information sheet (sent to project leads)

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Evaluation of the Big Lottery Fund Cardiac Rehabilitation Programme

Information sheet for projects

Overview

The Big Lottery Fund (BIG Lottery) has funded the Department of Health Sciences and Social Policy Research Unit (SPRU) at the University of York to undertake an evaluation of cardiac rehabilitation schemes based in primary health care in England. The schemes were set up through the British Heart Foundation (BHF) with funding from the Big Lottery Fund. This project is linked to but separate from the National Audit of Cardiac Rehabilitation also being carried out by the University of York.

The Cardiac Rehabilitation Programme has two main aims:

- to increase the uptake of cardiac rehabilitation services, particularly among groups of people who currently make low use of existing services and
- to drive sustainable improvements in the quality of services on offer to patients.

As part of its commitment to evaluate this and other programmes it funds, the Big Lottery Fund has funded the research to examine to what extent the programme has met its overall aims and how far individual schemes have achieved their goals. This includes examination of how effective services have been at improving access, involving patients, impacting on outcomes, improving quality of life and addressing inequalities.

Elements of the evaluation and timescale

The evaluation will commence in July 2005 and end in June 2008. There are three main elements to the evaluation:

- **Survey:** a brief, ongoing, survey of all the projects will be carried out. The purpose of this is to assess progress in achieving the aims, agreed with projects at the outset of the programme. The survey will commence in 2006 and will be carried out periodically by email through to 2008.

- **Case studies:** the results of the survey will be used to select eight case study sites for more detailed research. This work will involve interviews with staff and service users and their relatives, to be carried out in person and over the telephone. The purpose of this aspect of the evaluation is to identify and explore the factors that have helped and/or hindered progress, from both staff and users' perspectives.

- **Audit**: quantitative analysis of audit data kept by the projects will be examined in conjunction with the data from the other elements of the evaluation, to help examine the effectiveness of projects in improving access to and uptake of cardiac rehabilitation programmes for different groups of people.

Contacts

The evaluation is led by Professor Bob Lewin in the Department of Health Sciences. Other members of the research team are Corinna Petre (British Heart Foundation Care and Education Research Group, Department of Health Sciences) and Janet Heaton (Social Policy Research Unit).

For further information about the evaluation, please contact one of the researchers involved:

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Corinna Petre	cbp1@york.ac.uk 01904-321336	
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D2. Proforma for data extraction from application form

Evaluation of Cardiac Rehabilitation programme ~ Data extraction sheet

**To be copied to a spreadsheet for comparative analysis to help construct descriptive matrix.*

***Project ID**	

CONTACT DETAILS (CF BL FORM)

Lead organization	
***N organizations involved in project (state names of additional orgs)**	
Lead contact name	
Lead contact job title	
Lead contact address and postcode	
Lead contact telephone	
Lead contact email	
BHF CRC contact/rep	
BL/BHF own award reference	

AWARD DETAILS (CF BL FORM)

Title of project	
Amount awarded	
Start date	
End date	

EXISTING CR PROVISION (CF PROTOCOL)

Features of existing CR provision	
***Measures of existing usage/performance (with any dates)**	
***Main limitations/problems with existing CR provision**	

PROPOSED CR PROVISION (CF FORM; PROTOCOL)

***Aims in application (as stated in application)**	
***Evaluation aims agreed with CRCs (max 3)**	
***Target group(s) – socio-demographics** cf 5.4 – 5.7 + rural + carers/family	
***Target group(s) – medical**	
***Number of new staff to be appointed/funded through award**	
***Type/grade/time of staff to be appointed/funded through award**	
***How/where CR to be provided (through Lottery award)**	
***Award to be used to (NB say if brand new provision or extension of existing provision)**	
***Measures of expected usage/performance** cf 2.4 & 5.3	
***Inclu Road to Recovery/Papworth model?**	
***Inclu The Heart Manual?**	

STAFF INVOLVED WITH PROPOSED CR PROVISION

DOCUMENTS SUBMITTED WITH APPLICATION (exclu BL form, protocol, refs, EO policies)

D3. Sample survey questionnaire (first round)

EVALUATION OF BIG LOTTERY FUND CARDIAC REHABILITATION PROGRAMME

Dear

Progress with aims, barriers and facilitators

As you know every 3 months we are going to ask you to fill in a very brief questionnaire. All you need to do is fill in the blanks in your statement of aims and under each note down anything that is hindering you and anything that is helping you.

Your reply will only be seen by the researchers at the University of York. The results of the survey will only ever be presented in such a way that it is impossible to identify any centre. No other information will be divulged to the Lottery or the BHF or any of their employees. If in preparing the final report we want to highlight the work of a particular centre as an example of good or innovative practice we would write to that centre for their approval. This level of anonymity is to enable you to be absolutely honest with no fear of reprisals or embarrassment: essential if the results are to be accurate and therefore capable of helping improve future award schemes.

On this occasion you will receive the questionnaire by both email and by post, the final question asks how you would like to be contacted in the future.

Please return the survey, within two weeks of receipt, to Janet Heaton via email (jh35@york.ac.uk) or post (Janet Heaton, Research Fellow, Social Policy Research Unit (SPRU), University of York, York. YO10 5DD).

If you have any queries about the survey or the evaluation please contact Janet Heaton (see above, or tel: 01904 321950), or Corinna Petre (cbp1@york.ac.uk or tel 01904 321336).

WE KNOW YOU ARE ALL VERY BUSY - THANKS FOR YOUR HELP

Best wishes,

Janet Heaton

SURVEY POINT: JANUARY 2006

CONFIDENTIAL

Name of project:
Name of contact:

AIM 1: So far we have ___ patients using a [INDIVIDUALISED DETAIL ADDED] CR Programme

Our progress on Aim 1 is (please mark one box):

☐ On target ☐ Ahead of target ☐ Behind target

A) Things that have helped are:

B) Things that have hindered are:

AIM 2: To date we have enrolled ____ patients on a [INDIVIDUALISED DETAIL ADDED] programme

Our progress on Aim 2 is (please mark one box):

☐ On target ☐ Ahead of target ☐ Behind target

A) Things that have helped are:

B) Things that have hindered are:

AIM 3: To date we have ___ patients using the [INDIVIDUALISED DETAIL ADDED] CR Service

Our progress on Aim 3 is (please mark one box):

☐ On target ☐ Ahead of target ☐ Behind target

A) Things that have helped are:

B) Things that have hindered are:

Thank you

Project ID:

E. List of programmes funded under the Big Lottery Fund CR Programme

PCT	Programme title
Adur, Arun and Worthing Teaching PCT	Adur, Arun and Worthing Community Cardiac Rehabilitation Project
Barnet PCT	Mobile Outreach Service for Provision of Cardiac Rehabilitation to Barnet's local communities
Blackburn with Darwen PCT	Be Heart Smart
Blackwater Valley and Hart PCT	Expansion of BVHPCT and FPH Cardiac Rehabilitation Services
Bristol South and West PCT	BHF Cardiac Rehabilitation Project
Camden PCT	Empowering Patients to Optimise Attendance, Recovery and Secondary Prevention after Coronary Events
Central Cornwall PCT	Capture Cornwall
Central Suffolk PCT	Suffolk Cardiac Rehabilitation Programme
Dartford, Gravesham and Swanley PCT	Heart of the Community – Dartford, Gravesham & Swanley Community Cardiac Rehabilitation Programme
Daventry and South Northants PCT	Community Cardiac Rehabilitation: Improving services, access and patient choice in South Northants
East Cambridgeshire and Fenland PCT	Healing Hearts in Fenland
Eastern Birmingham PCT	Can I take your order? The facilitation of menu-driven cardiac rehabilitation service in primary care
Eastern Cheshire PCT	Comprehensive Multidisciplinary Cardiac Rehabilitation Services in Eastern Cheshire
Eastern Wakefield PCT	Cardiac Rehabilitation Programme
Ellesmere Port and Neston PCT	Restart with a Heart: Ellesmere Port's joint phase 3 and phase 4 Cardiac Rehabilitation Service
Exeter PCT	TLC: Training, Learning and Co-ordination. An integrated programme to support patients in Exeter
Gateshead PCT	Gateshead expansion of cardiac rehabilitation services for the ageing and less able population
Gedling PCT (Queen's Medical Centre)	Positive moves – cardiac rehabilitation in the community
Harrow PCT	Tackling the Challenges of Cardiac Rehabilitation using the Menu based Flexi Heart Plan

PCT	**Programme title**
Herefordshire PCT	Cardiac Rehabilitation Herefordshire
High Peak and Dales PCT	'Filling the gaps' The further development of cardiac rehabilitation services in North Derbyshire
Hillingdon PCT	The Hillingdon community HEART cardiac rehabilitation programme
Lincolnshire PCT	North Lincolnshire PCT Community Based Cardiac Rehabilitation Initiative
North & East Cornwall PCT	North and East Cornwall extending options in Cardiac Rehabilitation
North East Lincolnshire PCT	North East Lincolnshire PCT Cardiac Rehabilitation Programme
North Norfolk PCT	Healthy Living in Central Norfolk following Angioplasty
Northumberland PCT	Reaching into Rural Rehab – Building Northumberland's Cardiac Rehabilitation Programme
Salford PCT	Cardiac Rehabilitation Menu and Community Exercise Group Project
Scarborough, Whitby and Ryedale PCT	Community Cardiac Rehabilitation Programme
Somerset Coast PCT	West Somerset Cardiac Rehabilitation Patient Pathway Programme
Southampton City PCT	'Active Hearts' – Community Cardiac Event Recovery programme
South Sefton PCT	Coronary Revascularisation Home-based Intervention Service
Southwark PCT	The Camberwell and Peckham Rehabilitation Initiative - CAPRI
Western Sussex PCT	Creating Choice in Cardiac Rehabilitation
Wolverhampton City PCT	Locality based cardiac rehabilitation: responding to patients needs
Yorkshire Wolds and Coast PCT	Regional Exercise and Health Assisting Benefits Programme