

<i>(see guidance document for details on what should be included under headings below)</i>	Description	Network identified issues/problems	CC review comments	CC consensus feedback to Network
<b>Executive Summary</b>				
One page summary of key achievements over last year and future priority areas				
	<p>2005/06 has been a challenging year for the Yorkshire Cancer Research Network, as we have seen a high turnover of staff within the co-ordinating centre and the network. This period of organisational change continues and will be the overriding challenge for the year to come (see section 1.1). We have however continued to maintain recruitment: although lower than last year's 16.5 %, recruitment now stands at 13.8 % of incident cases. Entry into Randomised Controlled Trials is an encouraging 9.7% and bodes well for the implementation of the NCRN performance plan.</p> <p><b>Key achievements</b></p> <ul style="list-style-type: none"> <li>• Key achievements during the year include the development of a website aimed at patients, carers and the general public: <a href="http://www.researchandme.org.uk">www.researchandme.org.uk</a>. The aim of the website is to encourage people to find out more about research, contribute to discussion and to share information. It has been accessed by 25,000 people to date.</li> <li>• Breast and Colorectal portfolios continue to have strong recruitment, and we have seen increased recruitment for trials in haematology and prostate cancer.</li> <li>• We continue to work closely with our service network. This relationship continues to be positive and mutually supportive.</li> </ul> <p><b>Key Issues</b></p> <p>We have decided to take the opportunity of a current turnover of staff, along with the challenges of the new NCRN performance plan, to have a thorough review of YCRN strategy and organisation. Following a highly successful time-out day in May 2006, to which all YCRN core staff contributed, we have decided to develop a 1-year action plan for the immediate future, at the end of which we will develop a new 3-year Strategic Outline, with full consultation of all YCRN Stakeholders. Key issues for the 1-year plan were identified and included a need to:</p> <ul style="list-style-type: none"> <li>• re-evaluate the core team in order to ensure that maximum support is given to the network research teams.</li> <li>• review the role of Clinical Trial Co-ordinator currently based within the co-coordinating</li> </ul>			

<ul style="list-style-type: none"> <li>centre</li> <li>implement Service Level Agreements for all network funded posts</li> <li>improve the YCRN profile on the network Site Specific Groups and Cross Cutting Groups</li> <li>in co-operation with our network pathologists, apply to become an OnCore Biosample Donation Network.</li> </ul> <p><b>Future Priorities</b></p> <p>The immediate future priority for the network is to <b>re evaluate the core team</b> with the aim of placing as much resource out in the network. This will help to further increase the profile of YCRN, with clear objectives grounded in transparent service level agreements. Specific issues relating to <b>recruitment and follow-up can be addressed effectively and efficiently</b>. This improved network presence will allow us to provide more rigorous quality assurance. As part of the process we will develop a new Clinical Adviser role to assist in tumour specific portfolio development.</p> <p>Our other priority area is <b>implementing the NCRN portfolio development plan</b>. This will include the development of the palliative care and rare cancers portfolios. We already have strong links with research-active palliative care clinicians, and have provided pump-priming funding for palliative care research in the past; this portfolio will now be further supported. For rarer cancers, our plan will also address recruitment, and we have recently put in place additional research nurse support to help develop this portfolio.</p>				
<b>1 Organisation &amp; Development of Network</b>		Network identified issues/problems	CC review comments	CC consensus feedback to Network
1.1 Overview of network staffing profile & staff in post	The YCRN funds 18.1 whole time equivalent (WTE) staff across the network. This is a total of 25 individuals who directly support the set up and accrual for NCRN portfolio trials. The largest group of individuals employed by the YCRN continues to be research nurses/research officers equating to 11 WTE posts. These staff are responsible for actively	<ul style="list-style-type: none"> <li>In line with the NCRN performance plan it will be important to re-evaluate the distribution of network staff to ensure equity</li> </ul>		

	<p>recruiting patients into clinical trials across a range of disease sites and performing trial data capture. All Trust sites now have at least 0.5 WTE staff funded by the YCRN.</p> <p>The remainder of staff are based within the co-ordinating centre and comprise 2 WTE trial co-ordinators, 1 WTE regulatory officer, 1 office administrator, 1 WTE education and information officer, 1 WTE IT manager, 1 WTE network manager and 0.1 WTE clinical lead. The trial co-ordinators act as portfolio co-ordinators for the whole of the network working with hospital based staff to improve clinical trial activity. Their main responsibilities are to assist the development of network wide portfolios by promoting, educating, and trouble shooting. They have a clear remit within the network tumour groups. If required they assist the regulatory officer with ethics and R+D applications. The regulatory officer is a new post for the YCRN and is responsible for co-ordinating all Research Ethics and Research &amp; Development submissions across the Network. The post holder is required to manage between 30 and 40 trial set -ups per year across our 7 Trusts within the Network.</p> <p>In addition the YCRN also financially supports a further three posts in hospital service departments including radiotherapy, pharmacy and pathology which indirectly support NCRN activity.</p> <p>There have been 7 WTE staff leave the co-ordinating centre over a period of six months. This included the network manager, office manager and 5 Clinical trial co-ordinators. It is evident that this has been a particularly destabilising year. Although a new network manager took up post in April 3 posts remain vacant. Hence the opportunity to re-evaluate the core team before further appointments are made.</p> <p><b>Possible options</b> include:</p> <ol style="list-style-type: none"> <li>1. Continue with central hub and spoke model of staffing</li> <li>2. Devolve as many posts as possible to core posts in the cancer units</li> <li>3. Employ the Clinical Trial Co-ordinator (CTC) posts within the YCRN co-ordinating centre but base them within network trusts on a weekly/session basis</li> </ol>	<p>staff to ensure equity based on recruitment and priority areas. The YCRN has always been careful to ensure funding has been used to supplement not replace existing infrastructure. This will continue to be a challenge in light of the changes to R+D funding streams.</p> <ul style="list-style-type: none"> <li>• The cancer centre has also seen a number of non YCRN staff vacancies remaining unfilled until additional funds can be found this has undoubtedly affected recruitment</li> <li>• Re evaluation of the core team will take place before appointments to vacant posts within the coordinating centre are made.</li> <li>• Due to financial pressure most trusts have a mechanism in place to assess the need for reappointments this inevitable delay in recruitment is likely to effect accrual in the</li> </ul>		
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	<p>Two research nurse network posts have also been vacant leading to a suspension/reduction in recruitment within these Trusts.</p> <p>The YCRN is committed to providing both administrative and educational support to network research staff.</p>	<p>effect accrual in the longer term.</p> <ul style="list-style-type: none"> <li>• Most research staff in the network are still waiting for Agenda for Change banding outcomes. A cost of £40,000k has been accounted for to cover back pay requirements in the budget forecast 06/07</li> </ul>		
<p>1.2 T&amp;E</p>	<p>Training and career development are a high priority for the YCRN and has progressed in two ways. Firstly, by the continued implementation of the NCRN Training and Education Standard Operating Procedure (see 1.2.2), and secondly, through the ongoing development of the YCRN education programme (see 1.2.3). The YCRN continues to implement the systems it has already established for staff induction and training. Extensive details of the processes of the Training and Development of the YCRN plans are listed in last years Annual Report (1.2 - 1.2.5). Additional input for training has been provided by the Clinical Trials and Research Unit (CTRU) and the School of Healthcare Studies, both of the University of Leeds, the University of Sussex, and by the Institute of Clinical Research.</p> <p><b>1.2.1 Induction</b></p> <p>The YCRN supports an induction programme tailored to the needs of the individual.</p> <p>Newly appointed staffs (research nurses, data managers and trial coordinators) are placed within a clearly defined management structure. Their induction is supported by the Education and Information Manager. The induction timetable includes the following learning opportunities:</p> <ul style="list-style-type: none"> <li>• E leaning programmes for ICH/GCP and the EU Directive</li> <li>• ICH-GCP/ EU Directive study day</li> <li>• Working with experienced research nurses</li> <li>• Spending time with data managers and trial coordinators</li> <li>• Attending relevant clinics, MDT's and network meetings</li> </ul>			

- Meeting R&D and ethics committee departments
- Having an introduction to clinical trial SOP's
- Reviewing computer skills
- Meeting relevant medical staff

Every new member of staff is allocated a mentor, and is provided with opportunities for networking with other disciplines within the research community. Access to external staff and agencies, such as the Cancer Services Collaborative and the Clinical Trials and Research Unit is also included in the induction of a new member of staff. All new members of staff are invited to spend some time at the YCRN base at Cookridge, to develop an understanding of the role of the YCRN within the service network. Training needs are reviewed once more, after the first six weeks, by the Education and information Manager (Network Training Link).

**Induction Pack**

The YCRN now provides each new starter with an induction pack. This induction pack includes:

- an introduction to the YCRN, NCRN and UKCRN
- a basic introduction to cancer with an explanation of phases of clinical trials
- an explanation of the process of seeking R&D/ethical approval
- Maps, directions and relevant contacts for all the relevant cancer units
- SOP's explained
- A glossary of terms
- List of useful website addresses and suggested reading material

**E Learning programmes**

The YCRN has adopted an E leaning programme for ICH/GCP and the EU Directive for part of the induction for new starters. This has proved a very successful and beneficial venture. We are currently discussing the benefits of providing GCP and the EU Directive training to all members of the research community via e learning. These discussions are taking place with the CTRU and the ICR. The aim is to be able to provide a

complete training in these subjects that is both measurable in its outcomes, and convenient to complete. The success of this initial GCP and EU Directive programme may then lead to the development of other e learning programmes by 2008. Access for neighbouring network staff could also be open to discussion in the future.

### **1.2.2 Training and Education SOP**

The YCRN continues to implement the NCRN Training and Education SOP "Performing and documenting clinical team training". Core training in regulatory requirements, tumour specific training and trial specific training is provided to all staff. Access is given for further/additional training, and training records are maintained by the Education Manager, and available for audit. Where possible, training needs analysis is also carried out with non-funded staff throughout the network, who work along side YCRN funded staff on the NCRN portfolio. Personal training development plans run in parallel with the appraisal process.

### **1.2.3 Local Training**

The YCRN has developed a comprehensive training programme based on the needs of the network staff. This programme includes a variety of subjects including:

- Regulatory requirements
- Trial design
- Data handling and CRF design
- Recruitment
- Quality Assurance issues
- Statistics and further protocol development
- Consumer involvement
- Quality of life issues
- Audit preparation

This programme has incorporated local expertise as well as support from both the School of Healthcare Studies at the University of Leeds and the CTRU, also based at the University. The programme currently runs as a monthly series of sessions, lasting 2 hours.

Two study days have already taken place (Valid Informed Consent study day and Haematology study day). Both days were well attended and well received. As a result of their success, the Valid Informed Consent day has now been adopted by the UKCRN as a national study day, and the Haematology day has become an annual event for the Network attracting a national audience.

The YCRN educational programme has further developed links with the Institute of Clinical Research (ICR). The YCRN assisted in the creation of the ICR Yorkshire Forum, hosting the event in the first instance. The Forum provides academic support, learning opportunities and further professional development within the field of research. It delivers a series of further educational events relevant to practice, which complements the existing education programme. Two Members of the YCRN are on the steering committee of this forum.

#### **1.2.4 Attendance on NCRN and Local Training Courses**

See appendix 1.2.1 and 1.2.2

#### **1.2.5 Other Network Training and Development Initiatives**

ICH-GCP Training: To date the YCRN has registered 81 individuals who have received either local or national ICH-GCP training. It continues to provide this training for all staff throughout the network. A further 2 study days are planned accommodating 60 delegates in total.

Communication course: The YCRN has successfully completed the first run of the “Communicating Randomised Clinical Trials” course by Professor Leslie Fallowfield. Each series of 4 modules, which form the complete course, can accommodate 10 individuals. The course will continue to run through the next year both in the YCRN and across the North of England see section 5.

#### **Dissemination of Information:**

The YCRN Website. The website receives an average of over 10,000 hits

- The YCRN plans to run other tumour specific training days in the future. This could include study days for colorectal, breast and lung studies.

- YCRN Newsletter. We plan to produce a 3 monthly newsletter

	<p>per month. The website contains discussion forums, the latest information on trial portfolios and trial accrual, as well as a news and events section. This section highlights the training and education programme. Booking forms and further information on all the courses is available on line.</p> <p><u>Consumer Web site.</u> See point 4.</p> <p><u>RCN Update.</u> The YCRN promotes and circulates the RCN electronic update to all RCN members of the Research Team on a weekly basis. The RCN update circulates documents, calls for papers, promotes research finding and training, employment opportunities, disseminates the latest publications and informs members of future study days.</p> <p><u>YCRN Information leaflet.</u> The YCRN has composed an information leaflet aimed at clinicians and patients alike. This leaflet gives a brief outline of the work of the YCRN and an explanation of the key elements of taking part in a clinical trial. It lists some useful contacts and web site addresses, and invites the reader to contact the YCRN with any questions they may have in relation to research or clinical trials. This leaflet has been circulated to local hospital waiting areas and out patient clinics.</p> <p><u>YCRN Poster.</u> The YCRN is submitted a poster for display at the NCR1 Cancer Conference held in Birmingham in October 2005. The poster was entitled: "Promoting Excellence and Communication in Research within the Yorkshire Cancer Research Network." The aim of the poster was to promote the profile of the network and to share our structure and vision with others. The poster received positive feedback from delegates present.</p>	<p>for circulation throughout the network aimed at both health care professionals and service users. It will report on network recruitment and will include articles on conferences attended, contact details, educational information and news on trial development. It is intended that this newsletter will be a hard copy, produced professionally, and disseminated to local surgeries and libraries, as well as to the hospitals throughout the network. We feel that this initiative will further promote the importance of research throughout the region.</p>		
<p>1.3 Structures &amp; integration</p>	<p>The YCRN management board includes 15 members representing the network. The remit of the group is to provide strategic direction, approve policy and funding decisions. This board also feeds into the YCN Management board maintaining a close working relationship with the service network.</p>	<ul style="list-style-type: none"> <li>We were lacking clear Terms of Reference for the YCRN management board, so these have now been written and will</li> </ul>		

	<p>The YCRN is represented on the Network Tumour Groups by the disease site specific Clinical Trial Co-ordinators. Input regarding the research agenda could be stronger and Terms of Reference have now been developed defining the YCRNs role within the Groups. The YCRN contributes to the YCN tumour groups annual reports and is involved in the development of work programmes for 2006/07. In addition the YCRN maintains strong links with the cross cutting groups our most effective being Cancer Drug Therapy. We need to further establish our input into Histopathology and Radiology.</p> <p>The YCRN comprises a cancer centre based within the Leeds Teaching Hospitals Trust plus six Cancer Unit Hospital Trusts. The Cancer Units have defined referral pathways for each cancer site. All referrals for radiotherapy are made to the cancer centre along with all rare cancer referrals. The clinical trial co-ordinators provide a vital link in improving pathways for clinical trial activity. Communication across a large network is vital. YCRN staff visit units regularly acting as communication channels. The co-ordinating centre has attempted to hold quarterly meetings with each cancer unit to discuss performance. These have been performed with varying degrees of success.</p> <p>Collaboration continues with the pan-Northern group. This collaboration has proved invaluable for example the RCT Communications training developed by Lesley Fallowfield has been provided within networks as part of the roll out of the programme across the pan Northern group.</p> <p>The formal relationship with the NCRN accredited Clinical trials unit at Leeds University continues.</p> <p>The YCRN is developing links with its neighbouring stoke network and there is the future prospect of collaboration in areas such as T&amp;E.</p>	<p>be presented at the next meeting for agreement. The board still requires consumer representation</p> <ul style="list-style-type: none"> <li>• Terms of Reference for NSSGs are now defined</li> <li>• The YCRN needs to define its links with Histopathology and Radiology service network groups</li> <li>• After a period of reassessment the co-ordinating centre needs to maintain and improve it's cancer unit meetings Providing a clear remit for its quarterly meetings</li> </ul>		
<b>2 Accrual</b>		Network identified issues/problems	CC review comments	CC consensus feedback to Network
2.1 Overall accrual into NCRN portfolio	As can be seen from Appendix 2a, overall recruitment into NCRN trials has dropped by 16%. from 1655 in 2004/5 to 1382 in 2005/06. This figure	The drop in recruitment on the previous year is		

<p>NCRN portfolio studies</p>	<p>has dropped by 16%, from 1655 in 2004/5 to 1382 in 2005/06. This figure still represents 13.8% of the invasive cancer incidence for the population, so remains well above the NCRN goal of 10%. However, the success of the network in 2004/5 has clearly demonstrated our potential to operate at a higher level, and this is an important goal.</p>	<p>due to two main factors:</p> <p>Research staff around the network have not had the resources available to them to be able to recruit as many patients as the previous year</p> <p>Some large well recruiting trials have closed.</p>		
<p>2.2 Accrual by cancer site into NCRN Portfolio studies</p>	<p>As can be seen from Appendix 2b, accrual, as in previous years, is dominated by recruitment into Breast and Colorectal trials. These account for 43% of total network accrual.</p> <p>Accrual into trials for rare cancers such as Brain and Sarcoma have seen an increase in numbers in the reporting year. Brain recruitment increasing by 30% and Sarcoma recruitment increasing by 23%.</p> <p>Haematology and Prostate have also been strong recruiters this year, improving significantly on the previous years figures.</p> <p>The Miscellaneous sites section of the portfolio has seen recruitment drop significantly (360 patients) in 2005/06, this is due mainly to the closing of RAACS (Transport Study) and a much lower recruitment number for ATT (Attention Control Study).</p>			
<p>2.3 Quarterly accrual into NCRN Portfolio studies for network</p>	<p>Recruitment for 2005/06 is distributed amongst each quarter of the year, with levels ranging from 312 to 402 patients. The average number of patients recruited per quarter is 345.</p> <p>The 4th quarter of the year has the largest level of recruitment. (402)</p> <p>The quarterly totals are somewhat lower than the previous year, please see above for factors that have affected recruitment (2.1).</p>			
<p>2.4 Quarterly accrual into NCRN Portfolio studies by hospital</p>	<p><b>Airedale</b> – recruitment in 2005/06 has been lower than all previous years.</p>	<p>This is due to staffing issues within the trust. Recruitment into trials</p>		

	<p><b>Bradford</b> – recruitment has been extremely high in 2005/06, bettering all previous years by a significant margin. This is due mainly to high recruitment figures into AZURE (Breast trial) and SIGGAR (Colorectal trial).</p> <p><b>Calderdale &amp; Huddersfield</b> – continue to be high recruiters. 2005/06 saw a 22% in recruitment on the previous year.</p> <p><b>LTH</b> – continue to be the largest recruiter in YCRN. The trust accounting for over 50% of the networks total recruitment. The recruitment in 2005/06 has reduced due to resource issues and large trials closing to recruitment.</p> <p><b>Harrogate</b> – recruitment figures are very similar to the previous year.</p> <p><b>Mid Yorks</b> - recruitment figures are very similar to the previous year.</p> <p><b>York</b> – recruitment figures have dropped from the previous year (2004/05). This is due to RAACS (Transport Study) closing, York recruited 84 patients into this study.</p>	<p>was suspended for approximately 4 months.</p> <p>The recruitment in 2005/06 has reduced due to resource issues and large trials closing to recruitment.</p> <p>Key staff member has recently left the trust.</p> <p>This is due to RAACS (Transport Study) closing, York recruited 84 patients into this study.</p> <p>Network-wide Haematology Research Nurse has also left post recently which has impacted on the workload of existing staff. This issue is currently being worked through.</p>		
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2.5 Accrual of non cancer patients into NCRN studies (e.g. prevention, screening)	As can be seen from Appendix 2e, NSCCG was the largest recruiter in this section of the portfolio with 60 patients. Only 3 trials are included in this section.			
2.6 Eligibility screening data	<p>This graph (please see Appendix 2.f) is generated from the YCRN's recruitment system, it shows all patients that were screened for eligibility for a trial but did not actually enter the trial.</p> <p>This data is as accurate as it can be at this time but there may be data that has currently not been collected from other areas within the network.</p> <p>All data is supplied by research staff around the network.</p>	The YCRN is working hard to make sure this data is as accurate as possible.		
2.7 Details of patients in follow-up on NCRN trials	At present YCRN does not have accurate data on patients in follow-up on NCRN trials.	Work is currently being undertaken by YCRN Clinical Trial Coordinators to accurately document the follow-up burden within the network.		
2.8 Accrual into non-NCRN Portfolio studies	Accrual data for non-NCRN portfolio trials is currently not collected. Some units are happy to pass this data on but others have highlighted issues around confidentiality agreements with industry sponsors and are not prepared to allow us to collect this information.	<ul style="list-style-type: none"> <li>We are working towards a network wide agreement on collection of non NCRN data within our R+D forum</li> </ul>		
2.9 Plans for achieving/maintaining accrual	The forecast for 2006/07 must be realistic for the following reasons: extensive organisation change within the YCRN co-ordinating centre, general Trusts financial problems and the inevitable delay in re- appointing staff, changes to R+D funding streams. However it is reasonable to expect us to maintain recruitment at 12% with recruitment into RCT of between 7-9% We hope to achieve this by playing a more active role on the NSSGs and ensuring Trials are set up efficiently with minimal delay. This in turn allows us to maintain the enthusiasm of our clinicians and other research staff. In addition the YCRN is developing a Clinical Advisor Role to assist in portfolio development and recruitment (see comments)	<ul style="list-style-type: none"> <li>Expressions of interest will be sought in Aug/Sep 06 for the role of YCRN Clinical Advisor for each disease site.</li> <li>.The role will be closely allied with the YCRN Clinical</li> </ul>		

		Trial Coordinators and the YCRN Clinical Lead. In summary they will be expected to provide specialist advice and direction for the development of the network disease site portfolio		
2.10 Performance with reference to new weighted credit system	<p>In 2005/06 the YCRN recruited 1382 patients. This figure well exceeds the NCRN goal of 10% of incident cancer patients across the Network, standing in 2005/06 at 13.82%, 9.1% (910 patients) of this figure is made up of Randomised Controlled Trials and the other 4.72% (472 patients) made up of Non-Randomised Controlled Trials.</p> <p>This balance of trials within our portfolio gives the network a strong position when the weighted credit system is introduced.</p> <p>We are about to review the portfolio in line with the NCRN weighting system and will have a clearer idea of where our strengths and weaknesses lie from the coming year.</p>	<ul style="list-style-type: none"> <li>We are about to review the portfolio in line with the NCRN weighting system and will have a clearer idea of where our strengths and weaknesses lie from the coming year.</li> </ul>		
<b>3 Portfolio</b>		Network identified issues/problems	CC review comments	CC consensus feedback to Network
3.1 Overview of nature of network's current NCRN portfolio	The YCRN has a comprehensive and diverse portfolio covering common, intermediate and rare cancers. The vast majority of trials are treatment trials, using medicinal products. Breast and colorectal are well represented but particular emphasis should be placed on the lung portfolio in 2006/07.	<ul style="list-style-type: none"> <li>The YCRN must target the rare cancer portfolio and has placed a research nurse at the Cancer Centre</li> </ul>		

		to address this issue		
3.2 Local trials approval	X studies have been submitted for adoption this year	<ul style="list-style-type: none"> <li>The YCRN must continue to actively support and promote local trial adoption. The clinical trial co-ordinators and Clinical advisors are best placed to do this</li> </ul>		
3.3 Commercial trial activity (outside NCRN portfolio)	<p>There is extensive commercial trial activity taking place in the network particularly within the Cancer Centre. The Cancer Centre is well set up to cope with commercial trial work. Indeed the adult oncology research dept is strongly funded by this activity, with only minority funding coming from YCRN and charity sources.</p> <p>Accrual for these trials is currently not collected by the YCRN. Some units are happy to pass this data on but others have told us that confidentiality agreements with industry sponsors preclude this, and are not prepared to allow us to collect this information.</p>	<ul style="list-style-type: none"> <li>We are working towards a network wide agreement on collection of non NCRN data within our R+D forum</li> <li>Careful consideration will need to be given to the 'political' implication of commercial trial adoption when pre existing research departments have been principally involved in this type of research for more than ten years</li> </ul>		
3.4 Strategy for developing the network's NCRN portfolio	The YCRN will continue to work closely with cancer units, clinicians and other research staff to develop its local portfolio. Over time this will be in line with its agreed NCRN performance plan. Clear roles, responsibilities aims and objectives of the YCRN and it's co-ordinating staff will be communicated effectively to the network. We will continue to develop close links with the YCN and its related tumour groups and cross cutting			

<p>3.5 Regulatory &amp; Governance issues</p>	<p>groups.</p> <p>We established a YCRN R&amp;D Forum, which is now in its second year. It meets quarterly to discuss governance and regulatory issues, complex trials and training and education issues. The purpose of the group is to promote a unified approach across the network, and to anticipate and solve problems associated with individual NCRN trials (especially those involving excess treatment costs, non-standard investigations, etc).</p> <p>Since February 2006 the YCRN now has a central regulatory officer. The post holder is responsible for co-ordinating all Research Ethics and Research &amp; Development submissions across the Network. He is required to manage between 30 and 40 trials per year across our 7 Trusts within the Network.</p>	<ul style="list-style-type: none"> <li>The role of regulatory officer is already proving to be the most efficient means of successfully completing the R+D process. The role has possibilities to be developed further to include quality assurance.</li> </ul>		
<p><b>4 Consumer involvement</b></p>		<p>Network identified issues/problems</p>	<p>CC review comments</p>	<p>CC consensus feedback to Network</p>
<p>4.1 Consumer/user involvement in network activities</p>	<p>The YCRN is committed to supporting the role of the consumer in the research process, as outlined in the Research Governance Framework (2001 2.2.6) and Manual for Cancer Standard (2004)</p> <p>In September 2004, the YCRN facilitated the development of the YCRN User Partnership Group to look at ways patients and carers could become involved in the development of research projects at an early stage and also have their say in what projects were developed within the Yorkshire network. The group has developed a website aimed at patients, carers and the general public - <a href="http://www.researchandme.org.uk">www.researchandme.org.uk</a> . The aim of the website is to encourage people to find out more about research, contribute to discussions and to share information. The website has the support of the service network who is promoting the initiative amongst their own consumers.</p>			

	<p>The website has been accessed by 25,000 people to date. It has a number of web pages including news and events, discussion forums, reference documents and articles of interest. People accessing the site can email comments and suggestions of how to further develop. The site will continue to be developed in response to feedback received.</p> <p>The YCRN undertook a Patient Research Survey in October 2005. This identified a large number of patients who expressed an interest in becoming involved in developing research. The research group plans to develop a database of patients who gave permission and left contact details expressing an interest in involvement of research. These patients can then be contacted when network staff require patient involvement in the development of a research project. Currently 77 patients left contact details and they will be invited to an introductory meeting where they will receive more detailed information on how they can become involved. The introductory event will take place on 7<sup>th</sup> October at the bar Convent in York and will be open to patients, carers, the general public and health care professionals. There</p>			
<p>4.2 Status of Consumer Research Panels</p>	<p>In January 2006 David Howe was elected as the Chairman of the YCRN User Partnership group (patient representative) and Carol Sleigh as the co vice co-chair (professional member). The group continues to look for ways of increasing membership to allow a representative group of patients, carers and professionals across the disease sites.</p> <p>The group has forged links nationally with other user partnership and research groups. A number of presentations have been arranged for people in other groups to share their experiences.</p> <p>The group has finalised their terms of reference which include comprehensive definitions of roles and the workings of the group.</p>			
<p><b>5 Good Practice Initiatives</b></p>		<p>Network identified issues/problems</p>	<p>CC review comments</p>	<p>CC consensus feedback to Network</p>
<p>5.1 Examples of</p>				

<p>activities/initiatives developed in your network that have been particularly effective. Please identify examples of good practice that can be shared with other networks</p>	<p>The <b>Leslie Followfield Communication Course</b>. The YRCN acts as the co-ordinating centre for the provision of the course throughout seven of the northern cancer networks. The YCRN Training and Education manager has successfully secured additional funding to run the course.</p> <p>As previously discussed the <b>R+D forum</b> continues to successfully bring together the networks R+D managers to discuss standardising R+D processes.</p> <p>The <a href="http://www.researchandme.org.uk">www.researchandme.org.uk</a> website supported and promoted by the service network is a good example of a successful shared project.</p>			
<p><b>6. Future plans</b></p>		<p>Network identified issues/problems</p>	<p>CC review comments</p>	<p>CC consensus feedback to Network</p>
<p>Summary and challenges/pressure points</p>	<p>We have identified the need to collect 'real time' recruitment data from around the network. A project driven by the YCRN IT manager is underway to develop a web based system for the collection of recruitment data 'owned' by the network.</p> <p>Addressing the clinical trial follow-up burden around the network continues to be a challenge. We will be looking at this in the next year starting with a detailed collection of data driven by the clinical trial co-ordinators.</p>			
<p><b>7. Workplan for 2006/7</b></p>		<p>Network identified issues/problems</p>	<p>CC review comments</p>	<p>CC consensus feedback to Network</p>
	<p>With the appointment of a new network manager it was intended to produce a three year strategic plan. However due to the number of vacant posts within the co-ordinating centre and the network manager's maternity leave a one year action plan has been established with the view to 're-launch the YCRN in Summer 2007. This will involve input from all network stakeholders.</p> <p>The one year action plan involves</p> <ul style="list-style-type: none"> <li>• Re-evaluation of co-ordinating team particularly the role of the clinical trial co-ordinator</li> </ul>			

	<ul style="list-style-type: none"> <li>Detailed examination of the existing follow up burden around the network</li> <li>Successfully engaging palliative care and the development of a research portfolio</li> <li>Increase recruitment into rare cancer portfolio</li> <li>in co-operation with our network pathologists, apply to become an OnCore Biosample Donation Network.</li> </ul>			
<b>8. Additional Information</b>		Network identified issues/problems	CC review comments	CC consensus feedback to Network
<b>9. Contact information</b>				
	Please review and amend details as necessary and include as Appendix 3			

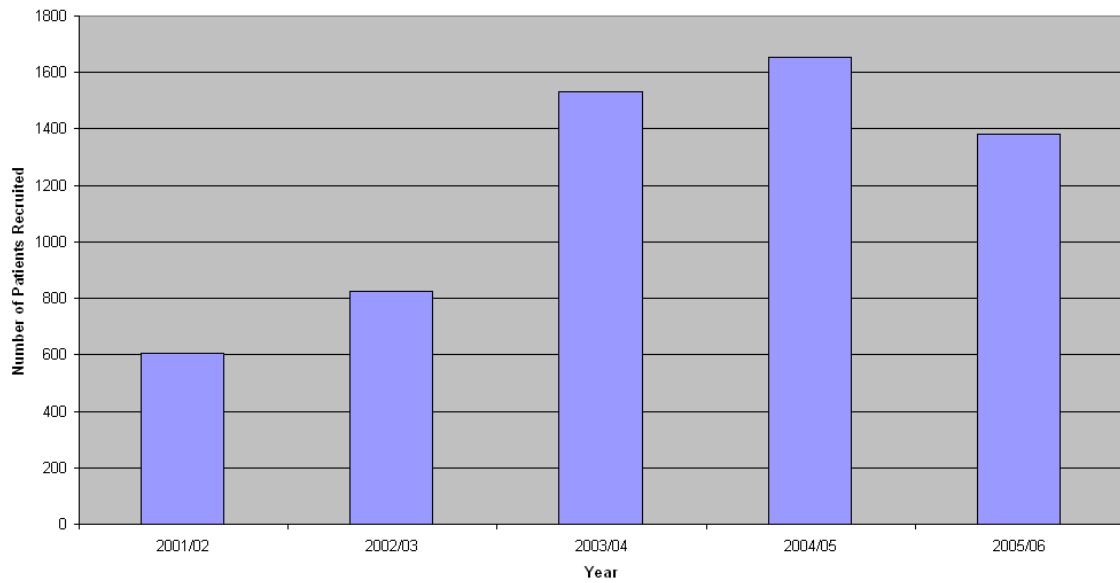
## Appendices

### 1.0 Accrual (Graphs)

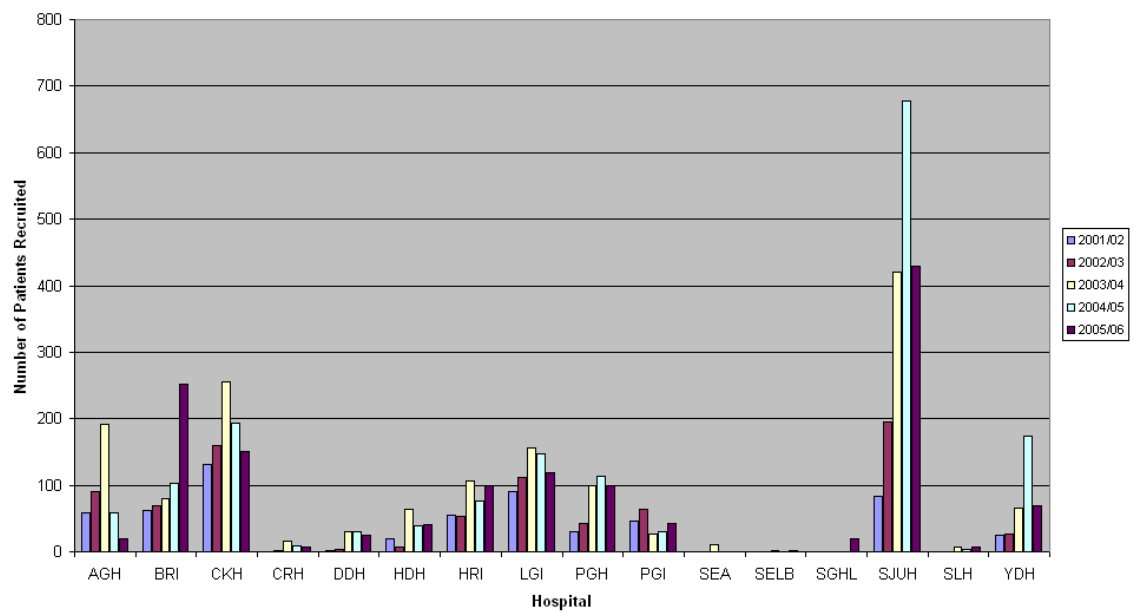
- 1.1 Annual accrual into NCRN Portfolio Studies (overall & by hospital)
- 1.2 Accrual by cancer site into NCRN Portfolio Studies
- 1.3 Quarterly accrual into NCRN Portfolio studies for network
- 1.4 Quarterly accrual into NCRN Portfolio studies by hospital

## Appendix 1.1

Annual Accrual for Yorkshire Cancer Research Network

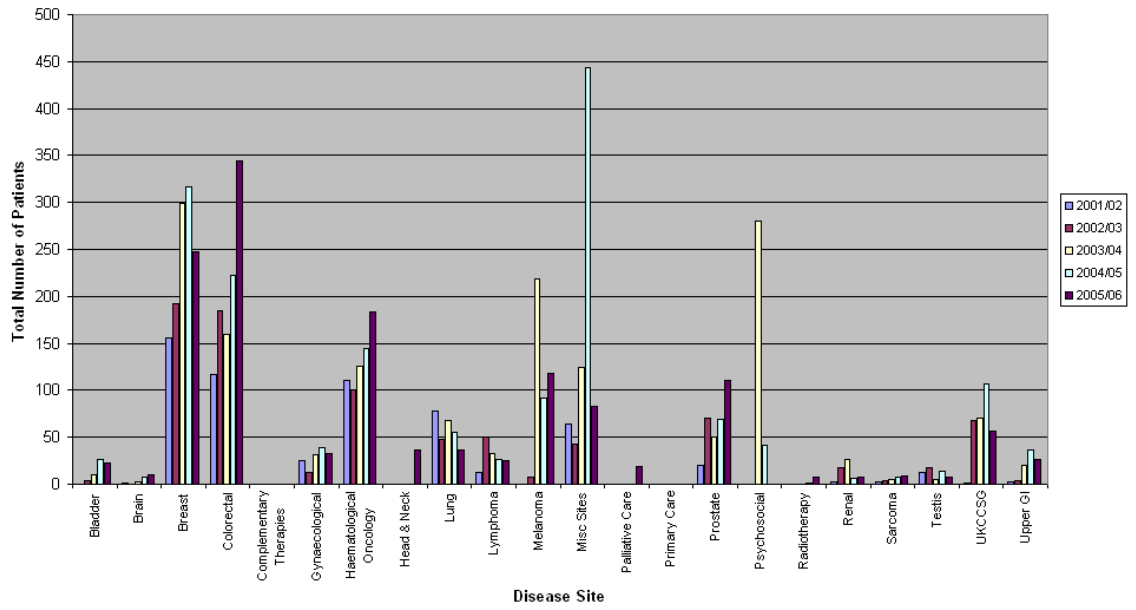


Annual Accrual for Yorkshire Cancer Research Network



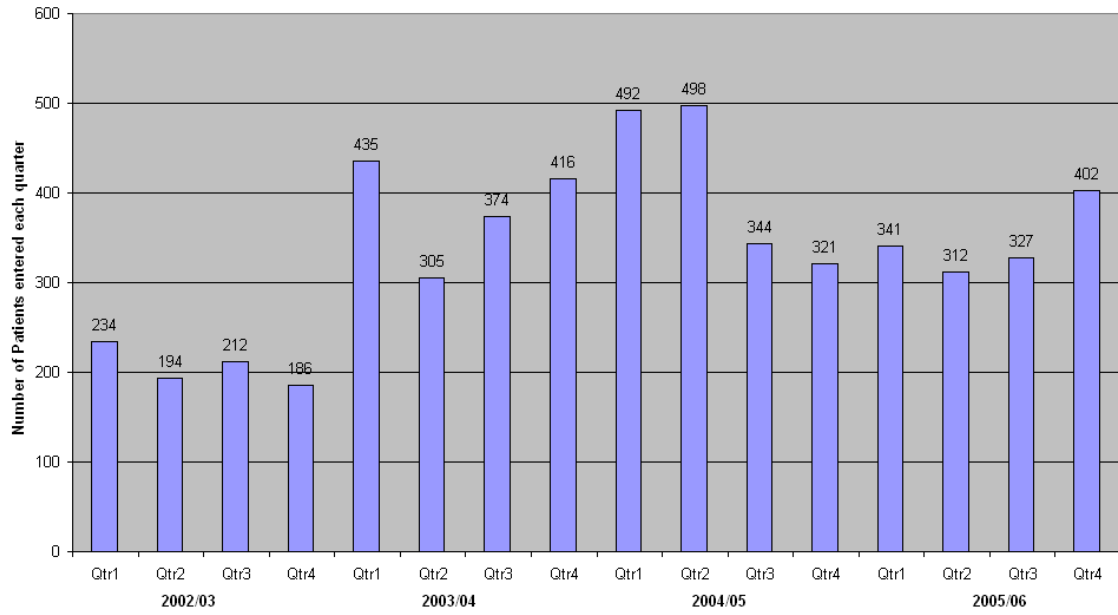
## Appendix 1.2

Annual Accrual by Cancer Site for Yorkshire Cancer Research Network



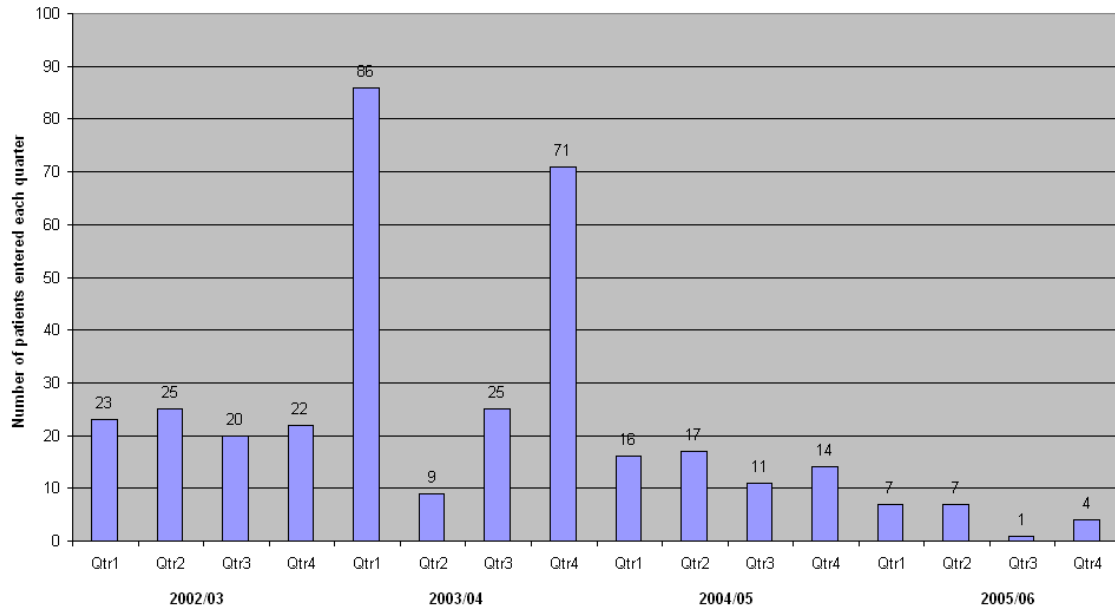
## Appendix 1.3

Quarterly Accrual for Yorkshire Cancer Research Network (Years 2 to 5)

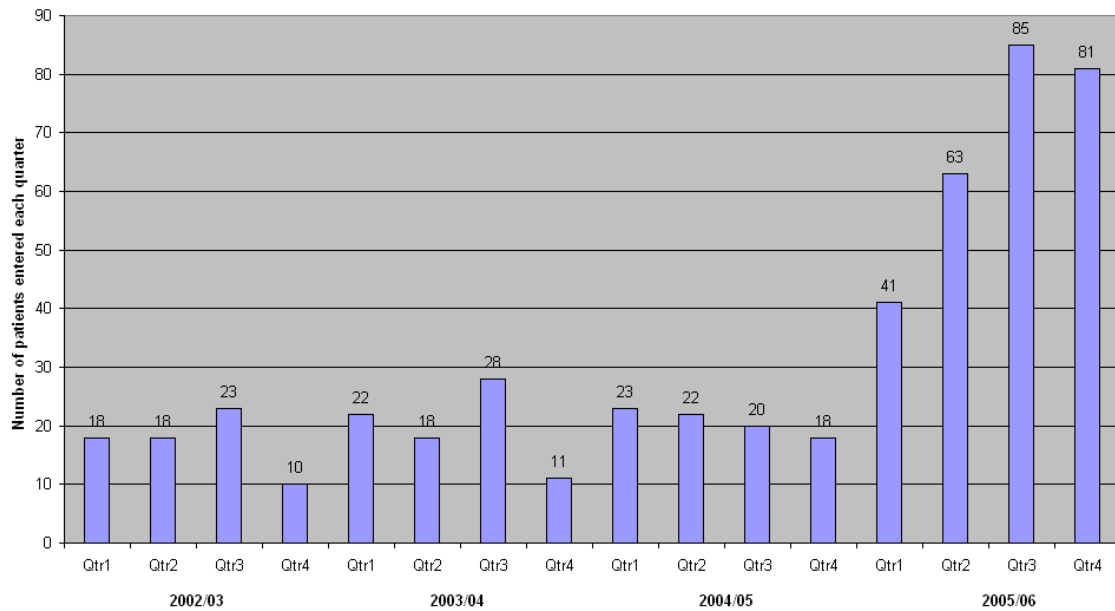


## Appendix 1.4

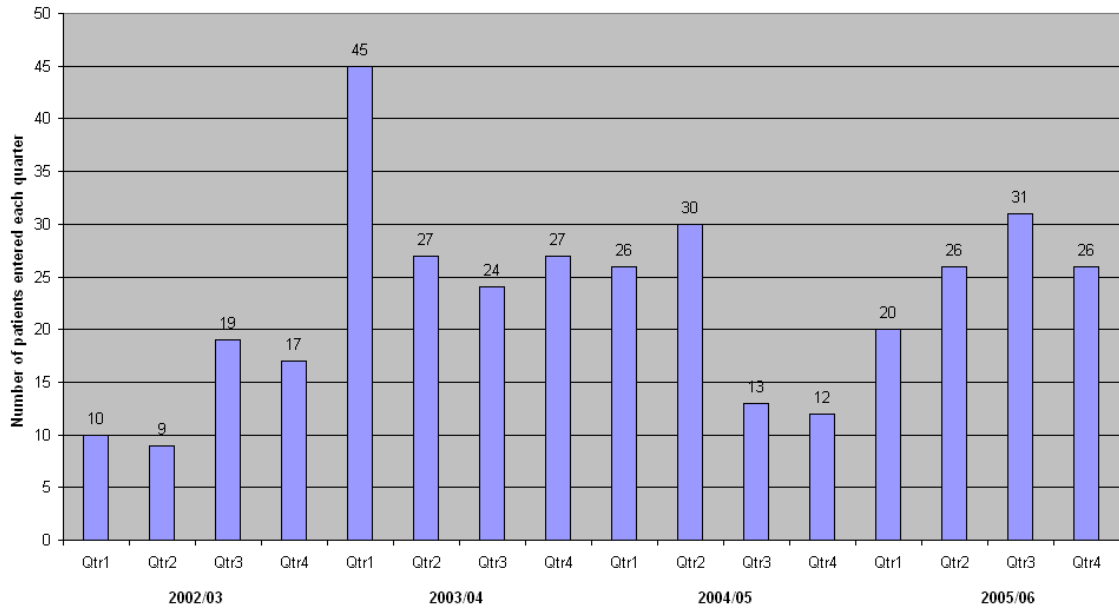
Quarterly Accrual for Airedale NHS Trust (Years 2 - 5)



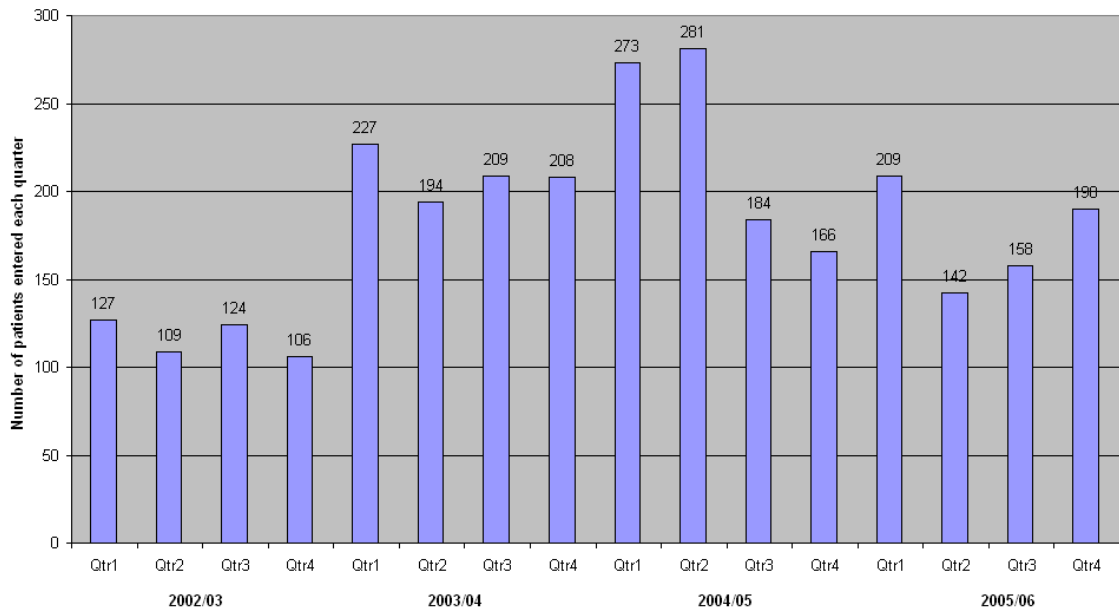
Quarterly Accrual for Bradford Teaching Hospitals NHS Foundation Trust (Years 2 - 5)



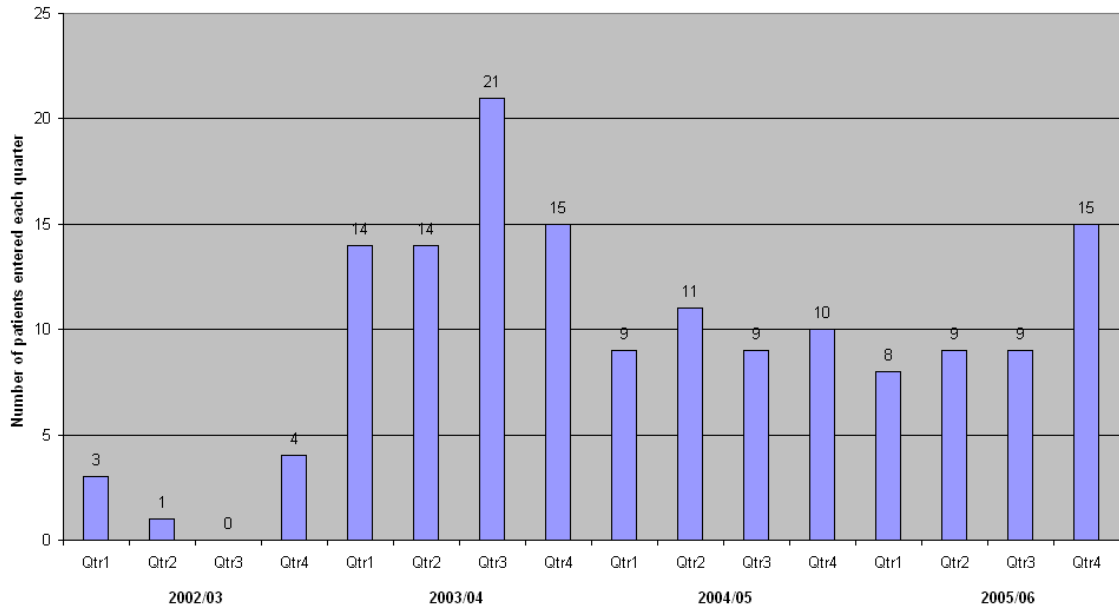
Quarterly Accrual for Calderdale & Huddersfield NHS Trust (Years 2 - 5)



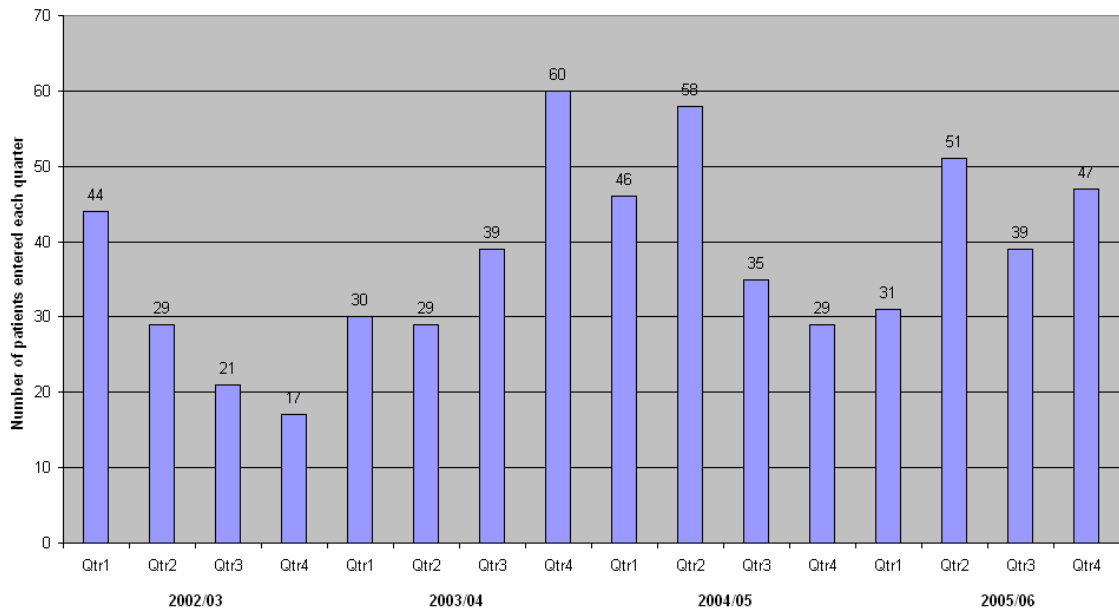
Quarterly Accrual for Leeds Teaching Hospitals NHS Trust (Years 2 - 5)



Quarterly Accrual for Harrogate & District NHS Foundation Trust (Years 2 - 5)



Quarterly Accrual for Mid Yorkshire Hospitals NHS Trust (Years 2 - 5)



Quarterly Accrual for York Health Services NHS Trust (Years 2 - 5)

