



# Marie Curie Cancer Care

Quality Account Report 2011/12

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# Contents

## Section one

Introduction by Chief Executive page 3

## Section two

Improving care for patients – our priorities for next year

Marie Curie Nursing Service page 12

Hospices page 14

Mandatory Statements of assurance from the board page 17

## Section three

Review of quality performance

Hospices page 21

Marie Curie Nursing Service page 23

## Section four

What others say about our Quality Account page 30

## Statement on quality from the Chief Executive of the organisation

Welcome to this year's Marie Curie Cancer Care Annual Quality Account Report.

The report is written to provide a balance to our financial reports and will focus on the quality of the care we provide to our patients.

The reporting period 2011/12 reflects the first year of operation of our 2011/14 strategic plan.

The 2011/14 strategic plan was developed to maintain our vision and our commitment to patients and families and has therefore kept the same name – *We Put Patients and Families First* – as a demonstration that our core vision and values are unchanged.

### Putting patients and families first

#### *Our vision for 2011/14*

Everyone with cancer and other life limiting illnesses will have the high quality care and support they need at the end of their life, in the place of their choice. During the first year of the strategy we have put in place the building blocks which will support the work over the next two years to ensure we meet our vision.

#### *Our core value*

We put patients and families first.

Our strategic plan to deliver this throughout 2011/14 sets out our plans to develop, expand and fund our work.

### Our key objectives continue to be:

#### *Better care*

- Delivering the right care, in the right place, at the right time
- Hospices being the hub of their communities
- Always improving quality

#### *Wider reach*

- Research and development to improve end of life care for everyone
- Being better known and understood
- Helping communities build better local care

## Stronger foundations

- Increasing the money we raise to fund our services
- Growing our volunteer support
- Improving our efficiency and effectiveness, always demonstrating value for money

## Providing care for terminally ill patients

Through our strategic plan we want to ensure that more patients will receive care from our Marie Curie Nurses and that those who are already receiving care will receive as much care as they need.

After the first year of our new strategic plan we have increased the amount of care we provide.

The figures for 2011/2012 are :

	Actual hours delivered	Increase achieved	Target increase
<b>Nursing hours</b>	1,206,450	5%	
<b>Nursing patient numbers</b>	23,737	18%	5% 
<b>Hospice non in-patient activity</b>	84,038	19%	2% 
<b>Hospice patient numbers</b>	7,877	7%	1% 

The growth we have seen is surprisingly strong given the position of NHS finances when Primary Care Organisations are seeking to reduce expenditure.

The Marie Curie Nursing Service has continued to grow despite pressure on NHS finances, achieving a rise of 18%. This is largely because the NHS has recognised that care provided in a patient's home at the end of life is what patients prefer and can be provided at a lower cost.

The high level of increase in patient numbers also reflects changes in the way Marie Curie nursing services are provided. We have developed Multi-visit and Rapid Response services where a nurse is likely to see more than one patient on a single shift.

## How do we decide what to include in this report?

The topics we have selected are those which patients and families have told us are important to them. Last year we learned through our patient survey that patients want good continuity of care. They do not want to be asked to repeat their medical story each time another nurse or health care professional attends to their needs. This means that we need to ensure good communication between our staff but also with other professionals involved in the patient's care.

Patients also told us that they want to know as early as possible when we will be providing care for them. This means that we need to ensure that our community nurses are matched and allocated to patients, according to patients' needs, as effectively as possible. In order to make this happen we must have effective IT systems, and processes which are responsive.

Patients also told us that their quality of life is important, and the care we provide to help them control their symptoms is vital. Patients reported that when staff respond quickly and effectively to their changing needs it makes a huge difference to them.

We regularly ask patients and families what they think about our services and what we can do to improve them. Last year we reported that we were undertaking a three year project to increase the amount of feedback we receive and to look at how we then turn that feedback into improvements to services.

As part of the Patient and Carer Feedback Project, a number of changes were made to the 2011/2012 survey with the aim of gathering more comprehensive feedback from a greater number of patients and families (from our hospices and the Marie Curie Nursing Service). These included asking people additional questions about symptom relief, spiritual and emotional support and the amount of care they received. For the first time questionnaires were also distributed to hospice community patients, in addition to in-patients, outpatients and day patients. By increasing the number of patients and families we hear from we are able to prioritise areas for improvement more effectively. Increased numbers of similar themed responses will give an indication of how many patients and families could benefit from changes we introduce. It may not always be right to make significant service changes based on comments from only one or two patients but if their views are reflected by a larger number of people then this gives more robust evidence that changes are needed.

We recognise that patients and families sometimes need help and support to complete our surveys and that they may be reluctant to give frank answers and suggestions if they are being asked the questions by Marie Curie staff. In order to address this we needed a different approach. We received excellent help from a large commercial organisation whose staff volunteered to undertake the survey for us by carrying out telephone interviews with patients and families who had used the Nursing Service and had agreed to take part. As in previous years for the hospices, the survey was administered by hospice volunteers and patients being cared for in the community were asked the survey questions over the telephone.

Some key highlights of the survey are:

- 72 volunteers delivered the survey.
- 214 people were called by the volunteers.
- 165 people were interviewed by the corporate volunteers.
- A further 24 were interviewed by the Belfast hospice volunteers by telephone making a total of 189 (32 patients and 157 carers).
- This was an increase of 3% on 2010.

These are reports of the thoughts of two of the people interviewed:

“ *The carer was very complimentary regarding the service he receives; he said he would not have been able to cope without the support of Marie Curie Care, that the spiritual support he has received is a 10 plus! The overall service received he felt was top notch.* ”

**South West Nursing Service region**

“ *The nurses really care and she feels they care. The nights the nurses come and stay it's marvellous for the carer. Everything has been excellent.* ”

**North West Nursing Service region**

The approach of using volunteers was successful and will be repeated for the 2012/13 survey but on a larger scale further increasing the number of people who take part and the amount of feedback we receive.

Last year we reported that we planned to increase the number of patients and carers we talked to. We have now completed the first year of a three year project to increase the amount of feedback we receive. We have begun to establish the best ways to analyse and act on what we are told by patients and families who use our services. To ensure patients and families are involved more as the project evolves, a carer is an active member of the project board and is now leading a working group specifically looking at how we demonstrate to others the action we have taken following their comments and suggestions.

We will report further on this next year.

## **Measuring and demonstrating quality**

### *Monitoring within Marie Curie Cancer Care*

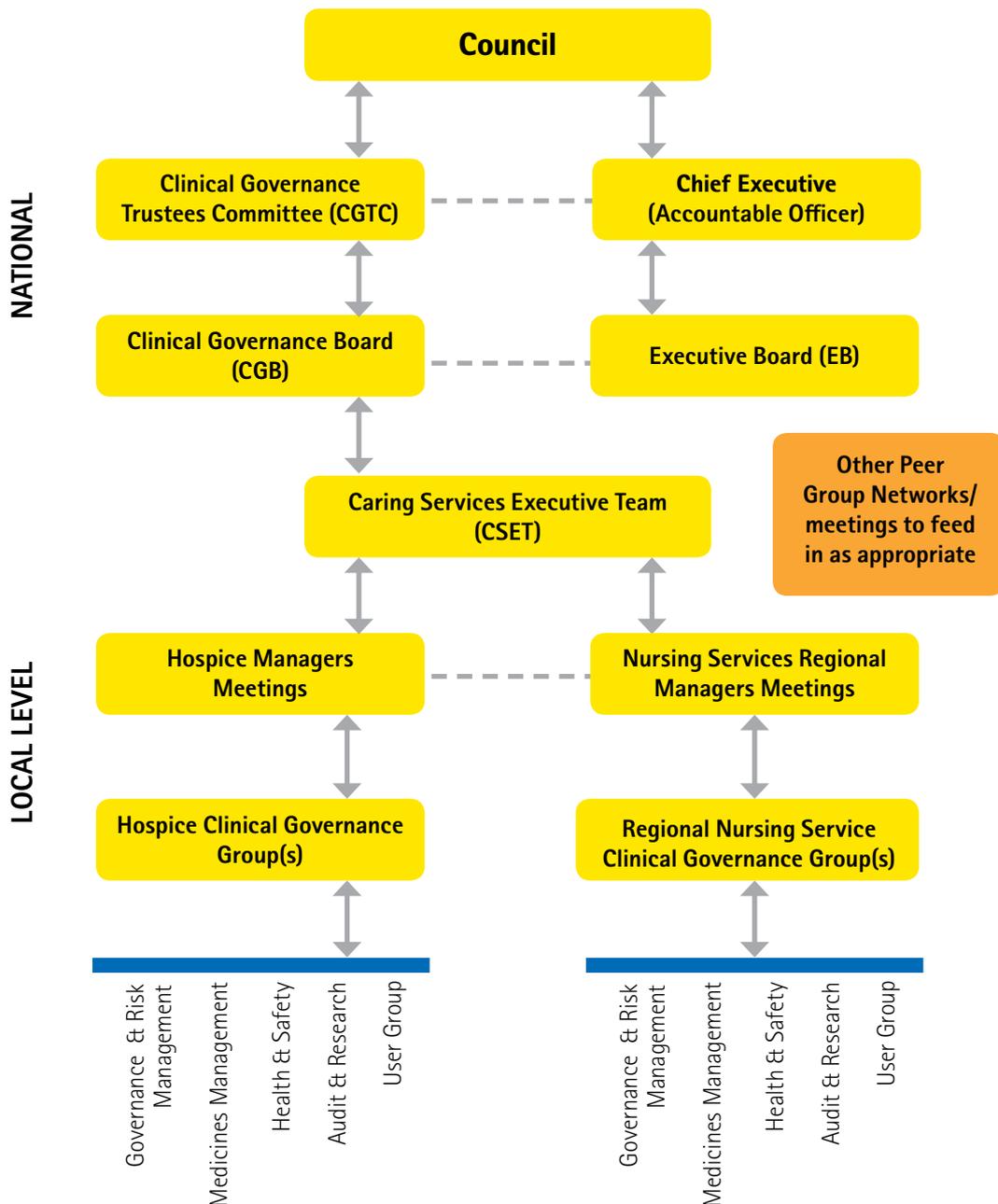
As an organisation with a focus on quality we know that it is important to challenge ourselves to make sure that what we do and continue to do always reflects the very best we can achieve. This important principle applies not only to the care we deliver to patients and families, but also to the management structures that support the quality of care we deliver. To test our existing structure for monitoring and reporting quality of care, we commissioned an independent audit just as we do for our financial management function. The results of this audit were helpful in identifying areas for improvement and how we could make our governance structures even more robust.

A plan to make changes is already well underway. Just as we have our financial division audited annually we are committed to testing these important structures every year to demonstrate continued good practice.

To support the recommendations from the audit a number of roles in Marie Curie's Caring Services division have been reviewed and adjusted and some key new roles identified. Work is underway to recruit to these important posts to ensure that we will be in a strong position to deliver the next phase of our three year strategic plan.

Within Marie Curie Cancer Care the proposed quality reporting structure is now as follows:

Marie Curie Cancer Care – Proposed quality reporting structure



The newly established Clinical Governance Board, which is chaired by the Chief Executive, has a very clear purpose: to ensure that high quality care is based on best practice. It will also ensure that the care is delivered by the right staff, with the right skills and training, at the right time and in the right place for each and every patient.

## External monitoring

Each of our services continues to be registered with the appropriate regulatory body as set out below:

England (hospices and nursing service)	Care Quality Commission
Scotland (hospices only)	Healthcare Improvement Scotland
Scotland (nursing service only)	Social Care and Social Work Improvement Scotland
Wales (hospice only)	Healthcare Inspectorate Wales
Wales (nursing service only)	Care and Social Services Inspectorate Wales
Northern Ireland (hospice and nursing service)	Regulation and Quality Improvement Authority

The regulators gather information about our services from a number of sources and use this to build a picture of the quality of services we provide. All our services are subject to announced or unannounced inspections at any time. This year the following inspections were carried out and some feedback from the inspectors is included.

The Regulation and Quality Improvement Authority inspected the Marie Curie Nursing Service in Northern Ireland in January 2012.

The RQIA report states:

*“ It is clear from this inspection that there are very good communication channels with primary and community care teams and other agencies. The referral and assessment process embraces the holistic, cross-professional nature of palliative care and allows for engagement with patients and their families in all aspects of the provision of care that is provided by the team. ”*

The Care and Social Services Inspectorate Wales undertook an inspection of the Marie Curie Nursing Service, Wales in January 2012.

The CSSIW report states:

“ *The Marie Curie Nursing Service had a comprehensive national quality assurance programme which covered the key elements of the service provided, which included the use of volunteers who undertook telephone interviews. Feedback from the last quality assurance report indicated that patients and carers rated the service as either very good or excellent and held the Marie Curie Nursing Service in high regard.* ”

The Care Quality Commission inspected the Liverpool hospice in February 2012. As part of their inspection they focussed on how well we meet their regulation about safeguarding people.

The CQC report states:

## **Safeguarding people who use services from abuse (Outcome 7)**

*What the outcome says:*

This is what people who use services should expect.

*People who use services:*

Are protected from abuse, or the risk of abuse, and their human rights are respected and upheld.

### **What we (the CQC) found**

*Our judgement*

There are minor concerns with Outcome 07: Safeguarding people who use services from abuse.

### **Our findings**

*What people who use the service experienced and told us*

Patients told us they felt safe at the hospice.

## Other evidence

The hospice had in place a current corporate policy and procedure for adult protection, recognising and reporting abuse. This contained information in respect of signs and awareness of abuse and procedures to follow in the event of suspected abuse. There were no policies or guidance information available to staff directly on the wards such as local policies and Department of Health guidance including 'No Secrets'. We were told the local authority's policies and procedures for safeguarding were available on the internet. The local Liverpool safeguarding authority's information was seen, this was held by the social work department and contained contact details for advice and reporting. Staff whom we interviewed demonstrated a good general awareness of abuse and what to do in the event of suspected abuse. They told us they would report concerns and seek advice from the social work department and managers at the hospice.

It was noted and acknowledged by the manager that no formal mandatory training in safeguarding occurred although the corporate policy stated staff and volunteers working directly with patients and families must attend training every two years in safeguarding awareness. We saw evidence of an online training package that was available for staff to undertake on a voluntary basis.

There was a whistleblowing policy and procedures in place. Staff whom we spoke to felt confident in reporting and that concerns would be dealt with appropriately in the need of disclosure or raising of concerns.

## Our judgement

Overall the provider is not meeting this essential standard.

People are at risk from potential abuse as staff are not trained in safeguarding nor do they have easy access to appropriate policies and guidance.

## Marie Curie Cancer Care response:

We have placed copies of the local safeguarding procedures in each clinical area ie: both wards, Day Therapy Unit and Outpatients Department and communicated their location to staff . All clinical staff are to complete the online Protection of Vulnerable Adults training by the end of October 2011 and face to face awareness sessions have been booked for all clinical staff. These will be completed by the end of July 2012. We will then ensure that specific training is refreshed every two years as part of our ongoing mandatory training programme.

The CQC report states:

*““ We spoke to a number of patients who expressed their extreme satisfaction with the service provided. Those we spoke to praised the staff and care given at the hospice saying: “They are excellent, they can’t do enough for you”; “The service is excellent – like a five star hotel”; “I can’t praise it enough!”; “This is the best place to be second to living at home. ””*

The Regulation and Quality Improvement Authority also inspected the Belfast hospice in March 2012.

The RQIA report states:

*““ Overall, the hospice was found to be providing a safe and effective service to patients and their representatives. ””*

Whilst the information and assurance we receive from these annual regulatory visits is important, we want to know that we keep our standards up all through the year. We continue to monitor and review a number of key areas such as patient and carer feedback, which includes complaints and compliments, incidents and near misses, clinical audit results and staff training. In addition, our assurance team carries out inspection visits of each hospice twice per year and these inspections will now be extended to our community nursing service. The quality assurance team is considering how we can involve service users in the inspection process; and with a reference group of carers with experience we will be exploring the most effective way to do this. We will ensure that these service users are appropriately trained and supported throughout their involvement.

In last year’s report we set out some very clear aspirations for areas where we wanted to see improvements, and our progress in these areas is reported in section three. We have also prioritised additional areas for improvement in our strategic plan which will form a new focus for us this year. These will be set out in section two.

My Executive Board colleagues and I are confident that the information set out in this report is a true reflection of quality in our current care provision

Signed off by THH on behalf of the Board



Sir Thomas Hughes-Hallett  
Chief Executive

# Improving care for patients – our priorities for improvement 2012/13

## Marie Curie Nursing Service

At present a patient can only receive care from the Marie Curie Nursing Service if they are referred to us by a healthcare professional, and this is usually the District Nurse. The District Nurse carries out an assessment of the patient's needs and develops a care plan which determines the amount of care the patient can receive from us. This is a model of care which we want to change as patients and families have told us that on some occasions they would like a different model of care, for example a short visit during the day, or that they need more care and support than they have been referred for.

### Priority 1 Clinical Effectiveness

#### *Patient assessment*

One of our key objectives is to deliver the right care, in the right place, at the right time.

In the last year we have introduced the new role of the Clinical Lead Nurse to the Nursing Service. The role enables us to increase the use of our specialist knowledge and experience in assessing both the type and amount of care the patient needs and the most appropriate package of care to deliver it, which should improve the overall experience for the patient. We will formally review how this new role impacts on patient experience through our regular surveys.

The Clinical Lead Nurse will have detailed knowledge of all the patients on their caseload and will therefore be in the best position to determine whether the level of support is correct and that the staff we are providing have the right skills to provide the care required.

The Clinical Lead Nurse will then be in a position to discuss with the referrer any changes in the patient's condition that may necessitate a change in the level or type of care provided.

We will monitor the impact of this different approach on patient and carer satisfaction and will comment further on this in next year's report

### Priority 2 Patient Safety

#### *Availability of notes in the home*

Up to date available records are vital to inform our staff of the patient's current clinical condition and any preferences they have about their care. They are key to ensuring patient safety and good continuity of care. As part of the annual clinical

audit programme for the Marie Curie Nursing Service, we assess the availability and content of patient records which our staff can access in the patient's home. Our audits have shown that on occasion key elements of the notes such as risk assessments and care plans are missing. Until now the only action our staff could take was to contact the District Nurse and ask for the information to be updated and made available. With the introduction of the Clinical Lead Nurse role we will be able to carry out key assessments ourselves, document our findings and ensure that there are up to date accurate care plans for the staff to work from. The content and availability of patient records will be audited again next year to check and monitor progress.

## Priority 3 Patient Experience

### *Patient and carer engagement*

Our vision for 2011/14 is that everyone with cancer and other life limiting illnesses will have the high quality care and support they need at the end of their life. To support this aim we need to involve the people we care for in developing and shaping the type of services we offer.

To achieve this we will develop the role of patient and carer champions within the community nursing service, with the aim of having a "patient and families/ carers' champion" in each of our nine nursing regions. These champions will be identified from our existing workforce. They will be responsible for ensuring that patients and their families/carers are involved in all decision making about their own care and are also given the opportunity to be involved in all appropriate projects and the design of new information and services. The champions will work as a team to share best practice across the nursing service.

In addition to strengthening the influence of patients and families the Regional Managers for the Marie Curie Nursing Service will be working with the Head of Carer Services and Engagement to ensure that we have patient/carers representation on each of our regional Clinical Governance Groups. These groups are responsible for locally monitoring the quality of care we provide and for driving continuous quality improvement.

## Hospices

### Priority 1 Clinical effectiveness

#### Symptom management

We know from our patients that if we can help them control their symptoms their quality of life improves.

“ *The patient loves coming to Day Therapy. (He) described his experience as: "Brilliant - they are the tops." Staff have encouraged him with gentle exercise which is positive, and he has never felt "pushed" - just encouraged. He described himself as chirpy and says staff will notice if he's quiet and will check he's feeling ok. His wife now has greater understanding of his condition as does he.* ”

**Volunteer recording patient feedback  
at Marie Curie Hospice, Bradford**

Last year we began a programme of improving the symptom management in our hospices. In 2010/2011 we focussed on improving the management of patients' breathlessness and the results of our first audit can be seen in section three.

Through our audit we identified that, although our medical and nursing teams assess patients for breathlessness and treat it well, they do not routinely use a standardised assessment method. This led to some inconsistencies in the way in which the patient's condition was managed from hospice to hospice. The recommendations from the audit are being implemented now in each hospice, led by our Nurse Consultant who specialises in the management of breathlessness. Progress will be monitored and a follow up audit will be carried out in 12 months to ensure the necessary improvements have been made.

### Priority 2 Patient safety

#### Medicines management

We know that for some patients the palliative care we provide will include a complex combination of drugs, using doses rarely used in other care settings. In recognition of this we have an absolute commitment to ensuring safe medicines management processes to protect patients whilst making sure they receive the medication they need. We recognise that good medicines management must be supported by an open culture of reporting when problems or potential problems are identified, investigated and resolved as a means of improving our working practice and the performance of our clinical teams.

Our priority for this year is to further improve our medicines management practice. We will audit our medicines management policies and practice across all hospices this year as the next step to improving this important area of our care.

“ (The patient) hadn't wanted to come to hospice but is so pleased she did come. Pain relief has been excellent. ”

**Volunteer recording patient feedback at Marie Curie Hospice, Bradford**

“ Complete turn around since mum came in, she now eats, has colour, not in pain so that is why I have put excellent for all questions. ”

**(Carer taking part in our annual user survey.)  
Marie Curie Hospice, Hampstead**

“ The doctors and nurses talk every day about your health, and sort tablets out to help. ”

**Marie Curie Hospice, Newcastle**

### *Priority 3 Patient experience*

We know that in order to develop the highest quality services for our patients and carers need we need to involve them at every stage. Firstly to identify areas for improvement and then to understand how we can make the changes required. Once the changes are made we need to check with them that we have achieved what we set out to do.

In order to truly put patients and carers at the heart of our services, we have appointed a patient and carer lead in each hospice. They are responsible for ensuring meaningful patient and family/carer engagement. This will include the inclusion of patients and families/carers on the new quality improvement groups, known as the Clinical Governance Groups. The lead will continue to ensure that every patient and family/carer is given the opportunity to tell us about their experience and that we will report back when we have taken the appropriate action. Where action is not taken (for example if the circumstances are out of our control) we will explain this to our patients and their families/carers and suggest alternatives. The work undertaken as a result of patient feedback will be reported to both the local and national monitoring boards.

The Carers and Engagement team will provide training and ongoing support to the patient and carer leads in order to ensure that the standards in the charity's updated patient and carer involvement policy, on such areas as information, design, delivery and feedback on services, are consistently delivered across the hospices.

Each hospice will be asked to demonstrate at least four service improvements in 2012/13 implemented as a direct result of patient and family engagement. Improvements do not need to be large scale change as we recognise that it is often the small details that make the biggest impact on people's experience.

““ *(The hospice provides) care, provides a home from home, good at boosting morale, explaining treatment and answering questions.* ”” **Marie Curie Hospice, Newcastle**

““ *Keep patient free from pain. Care for all their needs with dignity no matter what time of day or night. Also look after family of patient by keeping them up to date and supporting them at this most difficult time.* ”” **Marie Curie Hospice, Belfast**

““ *I have never been to the hospice. Fiona sorted my pain and discussed my wishes openly. Very confident now that I will stay at home to die.* ”” **Marie Curie Hospice, Edinburgh**

““ *The staff take time explaining how my Dad is every day and they can answer any questions I've got to ask. Also level of care my Dad is receiving is excellent.* ”” **Marie Curie Hospice, Glasgow**

““ *Care, warmth, and willingness to spend time with patient to establish needs. Treating patient as a whole person.* ”” **Marie Curie Hospice, Hampstead**

## Mandatory statements of assurance from the Board

The statements set out below are required by law and the wording set by the Department of Health; however numbers 2.1-2.4, 4, 6, 7 and 8 are not applicable to Marie Curie Cancer Care. For the statements which are applicable to Marie Curie Cancer Care the response is set out below. There is no requirement to report on regulators of our services in Scotland, Northern Ireland and Wales although information on services across the UK form the basis for this report.

### • Review of services

1) During 2011/12 Marie Curie Cancer Care provided services through nine hospices providing care for in-patients, outpatients and day care patients in addition to the community nursing service across the UK.

1.1) Marie Curie Cancer Care's Executive Board has reviewed all data available to it on the quality of care in those services.

1.2) The income generated by the NHS services reviewed in 2011/12 represents 100% of the total income generated from the provision of NHS services by Marie Curie Cancer Care for 2011/12.

### • Participation in clinical audits

2) The following statement is **Not applicable** to Marie Curie Cancer Care. Providers should complete the following statement:

During 2011/12 there were no national clinical audits or national confidential enquiries that covered NHS services that Marie Curie Cancer Care provides.

2.1) The following statement is **Not applicable** to Marie Curie Cancer Care: During that period there were no national clinical audits or national confidential enquiries which Marie Curie Cancer Care was eligible to participate in.

2.2) The following statement is **Not applicable** to Marie Curie Cancer Care: The national clinical audits and national confidential enquiries that Marie Curie Cancer Care was eligible to participate in during 2011/12 are as follows:

None

2.3) The following statement is **Not applicable** to Marie Curie Cancer Care: The national clinical audits and national confidential enquires that Marie Curie Cancer Care participated in during 2011/12 are as follows:

None

2.4) The following statement is **Not applicable** to Marie Curie Cancer Care: The national clinical audits and confidential enquiries that Marie Curie Cancer Care participated in, and for which data collection was completed during 2011/12, are listed below alongside

that number of cases submitted to each audit or enquiry as a percentage of the number of registered cases required by the terms of that audit or enquiry:

None

2.5) - 2.7) The reports of 13 local organisational clinical audits were reviewed by the provider in 2010/11. For all these audits the clinical teams have produced local action plans for improvements where necessary and in general they will be re-audited within the next 12 months to check for improvements. However, where results were outside an acceptable level the hospice or nursing service team will re audit within three months. The results are subject to review and approval by the Clinical Governance Board.

### *2011/12 National clinical audit programme*

The following tables set out the topics and timetable of the Marie Curie Cancer Care national clinical audit programme. These topics are based on the End of Life Care Quality Markers.

#### **Hospices**

<b>Audit topic</b>	<b>Data collection</b>
Liverpool Care Pathway (LCP)	April – June 2011
Do not attempt cardio pulmonary resuscitation (DNACPR)	June 2011
Admission & Discharge	July 2011
Pain Assessment	August 2011
Medicines Management	September 2011
Breathlessness	October – November 2011
Infection Control	December 2011
Preferred Place of Death	January 2012
Records Management	February 2012
Social Work	March – April 2012

#### **Marie Curie Nursing Service**

<b>Audit topic</b>	<b>Data collection</b>
Medicines Management	April 2011
Personal Protective Equipment (PPE)	May 2011
Documentation	September 2011
Falls	December 2011
Care at Time of Death	February 2012
Medicines Management	May 2012

The results of all these audits are reviewed by the Caring Services Executive Team and each local site has produced plans for improvements where necessary which are monitored by the Clinical Audit Group and reported to the national Clinical Governance Board.

- **Participation in clinical research**

3) Providers should complete the following statement:

The number of patients and carers receiving NHS services provided or sub-contracted by Marie Curie Cancer Care 2011/12 that were recruited during that period to participate in research approved by a research ethics committee was 18.

Patients at our hospices were involved in the following studies:

**Marie Curie Hospice, Hampstead**

Hospice/Service	Number of patients
Belfast	6
Hampstead	12
Total	18

An evaluation of a complex rehabilitative intervention for patients with advanced progressive recurrent cancer.

**Marie Curie Hospice, Belfast**

Identifying vulnerability in grief research project; a quantitative study to explore the different ways in which people react to bereavement.

- **Use of CQUIN payment framework**

4) The following statement is Not applicable to Marie Curie Cancer Care. Marie Curie Cancer Care income in 2010/11 was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. CQUINS are not currently being applied to our contracts.

- **Statements from the Care Quality Commission**

5) Marie Curie Cancer Care is required to register its services in England with the Care Quality Commission and its current registration status is fully registered. Marie Curie Cancer Care has the following conditions on registration:

Marie Curie Hospices registered to provide the following regulated activity:

- Accommodation for persons who require nursing or personal care
- Treatment of disease, disorder or injury
- Diagnostic and screening procedures

Marie Curie Nursing Service England is registered to provide the following regulated activity:

- Personal care
- Nursing care
- Treatment of disease, disorder or injury
- Diagnostic and screening procedures

The Care Quality Commission has not taken enforcement action against Marie Curie Cancer Care during 2011/12.

Marie Curie Cancer Care has not participated in any special reviews or investigations by the Care Quality Commission during the reporting period.

- **Data quality**

6) The following statement is **not applicable** to Marie Curie Cancer Care. Providers should complete the following statement on relevance of data quality and your actions to improve your Data Quality:

Marie Curie Cancer Care is not required to submit records during 2011/12 to the Secondary Uses service for inclusion in the Hospital Episode Statistics which are included in the latest published area.

- **Information Governance Toolkit attainment levels**

7) The following statement is Not applicable to Marie Curie Cancer Care. The following statement is required under the Data quality section:

[Name of provider] Information Governance Assessment Report overall score for [reporting period] was [percentage] and was graded [insert colour from IGT Grading Scheme].

- **Clinical coding error rate**

8) The following statement is Not applicable to Marie Curie Cancer Care. The following statement is required under the Data quality section:

Marie Curie Cancer Care was not subject to the Payment by Results clinical coding audit during 2011/12 by the Audit Commission.

## Review of quality performance

In last year's report we set out three priorities for improvements for our hospices and our community nursing service. All the areas identified were specifically selected as they would impact directly on the care our patients received, either through improving patient safety, clinical effectiveness or the patient experience. We will now look at how well we have met our aims.

### Last year's priorities – Hospices

#### *Priority 1 – Patient Safety*

##### **Infection prevention and control**

In last year's Quality Account we reported that we had inconsistencies in our infection control practice across our nine hospices which were highlighted by the first audit of the cleanliness standards we set in 2010. Following local actions to improve the areas identified a further national audit of infection control took place in December 2011 to assess progress.

The results of the audit as set out below are the overall compliance to all the standards reviewed. They demonstrate that in the last 12 months we have now achieved, maintained and demonstrated a high standard of cleanliness and infection control at each hospice.

The areas audited focused mainly on the physical environment and now that we are confident of good practice in this area we will look at other important elements of infection control such as hand hygiene.

The scores attained by each hospice are colour coded, red, amber or green, to demonstrate how well they have met the relevant standards.

(Green = 76 – 100%, Orange = 51 – 75%, Red = 0 – 50%)

	Belfast	Bradford	Edinburgh	Glasgow	Hampstead	Liverpool	Newcastle	Penarth	Solihull
2010	98%	78%	89%	81%	98%	76%	56%	98%	90%
2011	100%	99%	98%	99%	97%	92%	99%	96%	95%

## Priority 2 – Clinical Effectiveness

### Breathlessness

Last year we committed to ensuring that all patients experiencing breathlessness will have a detailed breathlessness assessment carried out. Breathlessness is a common and difficult symptom in advanced disease which can be frightening and distressing for both the patient and their family. This first national audit of breathlessness was based on standards which were drawn from the most robust evidence base for the clinical management of this symptom.

The high level results for the audit carried out at all our hospices are set out below.

This audit took place in October/ November 2011.

	2011
Standard 1: All (100%) patients experiencing dyspnoea (shortness of breath) will have a detailed breathlessness assessment carried out.	97%
Standard 2: All (100%) patients who are breathless on minimal exertion or at rest, and where potentially reversible causes have been excluded or treated optimally, will be offered a trial of opioids.	83%
Standard 3: All (100%) patients experiencing anxiety or panic attacks associated with their breathlessness will be offered a trial of benzodiazepine.	80%
Standard 4: All (100%) patients who remain breathless, despite potentially reversible causes being excluded or treated optimally, will be treated using a range of non pharmacological interventions from the multidisciplinary team.	60%

As a result of this audit we have identified the need for improvements particularly for standard 4 across all hospices. The clinician leading the audit made recommendations that are being implemented now, and this will include the routine use of standardised breathlessness assessment document in each hospice

We will be repeating this audit in 2012/13 as it remains a key priority due to the potential impact on patient care.

## Priority 3 – Patient experience

### Choosing where to die

We know from our research with patients and families that having the option to choose where they die is extremely important. This is true when people are well and as their medical condition changes. Over the last three years we have improved our approach to recording and sharing this essential information. We routinely check and record patient's wishes, including their wish not to discuss this if that is the case. We

recognise that as a patient's condition changes their preferred place of care and death may also change and we need to capture this change. We have now established standards about noting patient preferences which we have audited to assess our progress on achieving them.

We are confident we now have effective systems for recording patients' wishes and our future focus will be on establishing ways to more effectively ensure that we meet the wishes of patients and families and understanding why they have not always been achieved. We will report more on this next year.

### Choosing where to die

The following table shows overall compliance to the National Preferred Place of Death audit.

	Dec 2009	Feb 2011	Mar 2012
Standard 1: 100% of patients should have Preferred Place of Death or a record of variance recorded on PalCare/SystemOne	65%	85%	92%
Standard 2: Patients who express a preference should achieve their Preferred Place of Death.	63%	76%	83%
Standard 3: 100% of patients with an expressed Preferred Place of Death should (with the patient's consent) have that information shared with other relevant health professionals if they were discharged home or, for day and community patients, if they were living at home.	96%	97%	97%

## Last year's priorities – Marie Curie Nursing Service

### *Priority 1 Clinical Effectiveness*

#### Maximising efficiency

Following the introduction of a new IT system to allow us to more easily match patients' needs to nurses' skills and availability we have been working hard to reduce the number of times that we are unable to allocate a nurse to a patient when care has been requested.

Our new IT system has also allowed us to be more flexible in the ways in which we allocate work to our staff. The Marie Curie Nursing Service has continued to grow despite pressure on NHS finances achieving a rise of 18%. This is largely because the NHS has recognised that care provided in a patient's home at the end of life is what patients prefer and can be provided at a lower cost.

The high level of increase in patient numbers also reflects changes in the way Marie Curie Nursing Services are provided. The Marie Curie Nursing Service has developed multi-visit and rapid response services where a nurse is likely to see more than one patient on a single shift.

In February 2012 we saw the greatest ever number of patients in one month.

## *Priority 2 Patient safety*

### **Increasing effective partnership working**

We know that we can not deliver all the care and support that patients and families need during the course of a terminal illness and therefore we are increasingly working with other organisations to deliver seamless care.

During 2011/12 we have been actively looking for new opportunities for partnership working. Examples of these are the models of care now being provided in both Devon and Darlington.

In Devon we developed a new model of care delivery by joining up our community Nursing Service with the local Out of Hours team which is coordinated through the Urgent Care Centre. Together we have provided care to over 450 patients with end of life care needs since its start in August 2011. Working from three urgent care bases alongside GPs, paramedics, emergency care practitioners and District Nurses, 11 Marie Curie Nurses per night provide skilled specialist end of life care to help people meet their preferred place of care when they are dying.

In Darlington a rapid response team has been established with care being provided jointly by the Marie Curie Nursing Service and the team at St Teresa's Hospice. In order to monitor the effectiveness of the service, the team has a target to visit the patient's home/ care home within an hour in response to calls and to support discharge from hospice / hospital within six hours. In addition to providing care to the patient, the team also identifies carer support needs and will ensure referral to hospice outreach services and bereavement support services when required.

Following an initial trial period a formal partnership agreement has been signed and a combined staff group monitors the quality of service provided against the targets.

To further encourage good working relationships amongst the combined team, staff attend team meetings and clinical support together, as well as sharing joint training and education opportunities. The local Clinical Lead Nurse and Hospice Manager work closely together to ensure all operational matters are dealt with appropriately.

These services will be formally reviewed and evaluated, and we will report more on them next year.

## Priority 3 Patient experience

### **Becoming more accessible and providing better care**

We know from research and our patient and family surveys that patients want better continuity of care. We have several initiatives underway to evaluate whether we can improve access to care and continuity of care from the patient's perspective.

### **Marie Curie Managed Care Services**

During the past year we have begun working more closely with District Nurses to jointly assess the patient's needs and advise on the best ways to meet those needs. This modified model of care was started in two Health and Social Care Trusts in Northern Ireland and has now been expanded, due to its success, to the whole of Northern Ireland. The key findings from the first 12 month evaluation show that we are delivering more care to more patients. As part of the evaluation patients were asked about their experience of the service and 100% of the patients told us they were satisfied with the service. Also, nine out of 10 respondents felt that overall the service met their needs well. Needs included symptom control, having questions answered, ease of obtaining service and responding quickly to need.

We will be measuring the impact on patients through next year's user survey and we will be evaluating the perceptions of and impact on local stakeholders (District Nurses and commissioners) over the coming months. We will also be evaluating the nurses' perspectives of processes on the ground and their perception of the impact the service is having on patients. This should give a well rounded evaluation from multiple viewpoints.

Comparing the 12 months before the implementation of the model in the Western and Belfast Health and Social Care Trusts to the first year of the Managed Care Model in these areas

- The proportion of new patients with non-malignant diagnoses supported by the Nursing Service increased from 12% to 19% of patients
- There was a 30% increase in the overall number of patients seen
- There was a 60% increase in the overall number of hours of care delivered
- There was a 74% increase in the overall number of visits delivered
- There was a 23% increase in the average number of hours of care per person
- There was a 34% increase in the average number of visits per person
- There was an 8% decrease in the number of hours per visit

This model of care provision is now being trialled in South East Essex and Neath Port Talbot. Both of these services will also be formally evaluated and we will report on these evaluations in next year's report.

## **Self referral**

We know that one of the main barriers to patients receiving our services is the requirement for them to be referred to us by the District Nurse or another healthcare professional already involved with their care. This is a barrier not only to access but also to patients being able to exercise their choice. Working in collaboration with the local NHS organisations we began a project in Derbyshire last year. The project will run for two years and will help us understand the true demand for Marie Curie Nursing Service in Derbyshire, the advantages and challenges of allowing patients to refer themselves for care from nursing service, and the extent to which patients or their families will self refer.

To date the numbers have been small with 26 enquires to the service from patients, not all of whom have gone on to receive care. However we will continue to monitor this.

## **Rapid response services**

We have continued to grow the number of rapid response services which can provide short episodes of urgent care to patients in the community. These are increasingly being delivered in partnership with others as in our Devon and Darlington examples.

## **Co-ordination centre**

We are now managing the end of life care co-ordination centre in South of Tyne and Wear. The coordination centre will provide patients and carers with a single point of contact to access information about the care they are receiving or may be entitled to receive. The use of a single point of contact will improve continuity of care by ensuring all care providers involved in looking after the patient have the same up to date information about the patient and carer and their needs and wishes.

## **Marie Curie Helper**

The Marie Curie Helper Service is delivered by a growing team of volunteers who provide practical and emotional support, short breaks for carers and information on relevant local services to anyone with a life limiting illness, their carers and families. Support is given in a number of ways including one-to-one meetings in the patient's home, over the telephone, or by accompanying the terminally ill person on a visit or appointment.

The Helper Service is currently operational in four sites across England to test the service in four very different geographical locations both rural and urban. As part of the evaluation of the service carried out by IPSOS MORI on our behalf we asked people what they thought. Their feedback suggests that overall they rated the service very highly: 90% rated the overall experience as very good or excellent, and 90% felt that the service had a positive impact on their lives. In interviews people told us the key benefits of the service included emotional support, companionship, practical support and information provision.

Emotional support was seen as the key factor distinguishing the Marie Curie Helper service from other services. Having a Marie Curie Helper meant that terminally ill people had an outlet for their thoughts and feelings. They talked about what was worrying them that day or their feelings about their situation – these were things they felt they could not (or should not) share with their health professionals.

Marie Curie Helpers frequently offered companionship to the terminally ill person, ranging from something akin to a 'sitting service', to something much closer to friendship. The parties would hold general conversations, chat about common interests or take part in shared activities and hobbies (eg shopping, meals out, sports matches).

Practical support provided by Marie Curie Helpers included small tasks around the home, sometimes taking the person shopping or to necessary appointments. This meant they were able to do things they would not otherwise have been able to do.

The evaluation suggested that Marie Curie Helpers were less likely to provide information about services compared to other types of support. However where information was provided, it meant that terminally ill people were able to access services they would not otherwise have known about.

The findings from the evaluation will inform the future development of the Marie Curie Helper service in existing and additional sites. We will continue to listen to patients and families and adapt our services to ensure they continue to meet their needs.

### **Investment in palliative and end of life care research**

Marie Curie Cancer Care is committed to improving the quality of care and the patient experience at the end of life for all patients through investment in research.

We have demonstrated this commitment by investing in a number of research studies over the next five years. The areas of research we are supporting range from clinical studies to improve symptom control for patients to social studies into how volunteers might be used in end of life care to better support carers.

As part of our research investment, Marie Curie is funding a number of studies which form part of the National Institute for Health Research. Examples of four of these important studies are set out below. The aim of all of them is to directly influence improvements to patient care.

Research Study	Number of participants recruited
Professor Marie Fallon, University of Edinburgh, KPS - Ketamine in Pain Study - A randomised double-blind controlled trial of ketamine versus placebo in conjunction with best pain management in neuropathic pain in cancer patients	19 patients recruited between January and March, 2012
Professor Sheila Payne, Lancaster University, 'Unpacking the home': family carers' reflections on dying at home	14 carers recruited between April, 2011 and March, 2012
Professor Jane Seymour, University of Nottingham, Nurses decisions to use anticipatory prescriptions	43 health care professionals recruited between April, 2011 and March, 2012
Dr Debra Howell, University of York, Exploration of factors associated with place of care and place of death in patients with haematological malignancies	276 patients recruited between April, 2011 and March, 2012.

Marie Curie has made a considerable financial commitment to research in end of life care. £1million per year for six years has been committed to the Marie Curie Cancer Care Research Programme which is open to applications to fund research into specific themes which have the potential to benefit the care of people at the end of their lives and their families. Themes are selected after consulting experts from inside and outside the charity, and funding is awarded on the basis of peer review and open competition. We work closely with Cancer Research UK to ensure this money is used to support those research projects that are most likely to improve our knowledge and therefore impact on future patient care.

We also fund three research facilities: the Marie Curie Palliative Care Research Unit at University College London, the Marie Curie Palliative Care Institute Liverpool and the Marie Curie Palliative Care Research Centre, Cardiff. Research activity also takes place in our hospices.

At the Marie Curie Palliative Care Research Unit in London, a further £1 million has been made available over three years to try to establish what specific interventions are most effective for patients with advanced dementia at the end of their lives.

In 2011/12, 32 peer-reviewed articles were published in key journals on palliative and end of life care resulting from research activities at the three research facilities.

In addition to improving care for patients through research, Marie Curie Cancer Care is committed to driving improvements for all patients by improving the knowledge and evidence of what good care is. In order to do this we continue to hold our annual Marie Curie Palliative Care Research Conference which is expanding year on year. It is held annually in collaboration with the Royal Society of Medicine and in 2012, the conference presented the latest evidence on symptom control relevant to palliative and end of life care. Approximately 200 participants attend to share the latest information and knowledge.

In addition to the conference we are increasing the amount of research being undertaken at our hospices and, more importantly, then put into practice. We have extended our Research Facilitator Programme from the Marie Curie Hospice in Belfast to two new sites, Edinburgh and Solihull, in 2011/12: The purpose of these posts is to embed research into our normal activity to ensure that our patients can continue to take part in research studies if they wish and that they and our staff are given access to research where they want it. This will ensure our patients receive the highest quality, evidence-based care at the end of life and will encourage our clinical staff to develop research skills and maintain the highest standards of evidence based practice.

In all areas of our work we put patients and families first and continually strive to improve the quality of care we provide to patients at the end of life and the support we give to their families and carers.

## What others say about our Quality Account

Statements from Local Involvement Networks (LiNK), Overview and Scrutiny Committees and (OSC) and PCTs

### NHS Lincolnshire Commentary for Marie Curie Quality Account 2011/12

In terms of performance in 2011/12 there are a number of issues worthy of note within the Marie Curie Quality Account. For example in relation to compliance with the National Preferred Place of Death Audit, 83% of patients who expressed a preference achieved their Preferred Place of Death. NHS Lincolnshire continues to work with Marie Curie and other providers of end of life care to develop partnership relationships, ensuring that providers work collaboratively to support patient choice in this area.

NHS Lincolnshire is pleased to note that Marie Curie has employed an innovative approach in order to seek feedback on services from patients and families, getting help from a large commercial organisation whose staff volunteered to undertake the survey by carrying out telephone interviews with patients and families who had used the Nursing Service. Further, it is noted that a number of changes were made to the 2011/2012 survey with the aim of gathering more comprehensive feedback from a greater number of patients and families (from hospices and the nursing service), including asking additional questions about symptom relief, spiritual and emotional support and the amount of care they received.

NHS Lincolnshire also commends the organisation on development of the rapid response services which can provide short episodes of urgent care to patients in the community. These are increasingly being delivered in partnership with other providers to enhance the range and quality of palliative care services.

It is also worthy to note that Marie Curie commissioned an independent audit to test the existing structure for monitoring and reporting quality of care, as this demonstrates a commitment to delivering a quality service.

Examples given within the Quality Account highlighted areas of service that demonstrate high quality care using the three key areas of effectiveness, safety and patient experience. NHS Lincolnshire particularly welcomes the focus placed on ensuring that more patients will receive care from Marie Curie Nurses and that those who are already receiving care will receive as much care as they need. Further, that after the first year of the new strategic plan, the organisation has increased the amount of care it provides.

Marie Curie Cancer Care income in 2011/12 was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. CQUIN payments are not currently being applied to this contract.

NHS Lincolnshire notes that the Trust's current registration status with the Care Quality Commission is fully registered. Marie Curie Cancer Care has the following conditions on registration:

Marie Curie Hospices are registered to provide the following regulated activity:

- Accommodation for persons who require nursing or personal care
- Treatment of disease, disorder or injury
- Diagnostic and screening procedures

Marie Curie Nursing Service England is registered to provide the following regulated activity:

- Personal care
- Nursing care
- Treatment of disease, disorder or injury
- Diagnostic and screening procedures

The Care Quality Commission has not taken enforcement action against Marie Curie Cancer Care during 2011/12.

Further, NHS Lincolnshire notes that Marie Curie Cancer Care has not participated in any special reviews or investigations by the Care Quality Commission during the reporting period.

### **Areas for Improvement 2012/13**

NHS Lincolnshire endorses the areas identified for improvement for 2012/13 and the associated initiatives as detailed within the Marie Curie Quality Account as:

## **Marie Curie Community Nursing Services**

### *Priority one: Clinical Effectiveness*

#### **Patient assessment**

### *Priority two: Patient Safety*

#### **Availability of notes in the home**

### *Priority three: Patient Experience.*

#### **Patient and Carer engagement**

## Marie Curie Hospices

### *Priority one: Clinical Effectiveness*

#### **Symptom Management**

### *Priority two: Patient Safety*

#### **Medicines Management**

### *Priority three: Patient Experience*

#### **Demonstrate at least four service improvements in 2012/13 implemented as a direct result of patient and family engagement.**

Whilst NHS Lincolnshire does not commission Marie Curie Hospice services, NHS Lincolnshire does commission the Marie Curie Nursing Service and the Rapid Response Service. Commissioning high quality, safe patient services is our highest priority and the areas identified will enhance the patient experience and improve patient safety and clinical outcomes.

NHS Lincolnshire endorses the accuracy of the information presented within the Marie Curie Quality Account and the overall quality programme performance will be reviewed through the formal contract quality review process and triangulation through patient experience surveys.

#### **E Butterworth – Director of Quality & Involvement, NHS Lincolnshire**

Thank you for the invitation to comment on the Marie Curie Cancer Care Quality Account. We note that you are required to submit this to the Lambeth Health Overview and Scrutiny Committee as your principal offices are based in the borough. However, we further note that the QA refers to services provided across the UK and particularly at the nine Marie Curie Hospices (none of which are in Lambeth).

We believe that there should be some form of national oversight of the QAs of national organisations. However we feel it is questionable whether a health OSC is best placed to comment on the merits of a QA solely on the basis of head office location (rather than experience and knowledge of a provider); nor do we consider it appropriate that you should be required to potentially make your QA reflective of (Lambeth) local priorities or locally meaningful when your work is on a national basis. This reflects our position on receiving the QA in previous years and subsequent letters to, and discussions with, the Department of Health on the process.

Notwithstanding this response in relation to the QA, Lambeth Council's Health and Adult Services Scrutiny Sub Committee would wish to acknowledge and extend thanks to Marie Curie Cancer Care for the valuable work undertaken by the organisation.

**Elaine Carter, Lead Scrutiny Officer, London Borough of Lambeth**

LINK Southwark would like to thank you for sending the 2011/12 Quality Account. However, we are unable to provide a comment on this year's Account. While the work of Marie Curie is extremely important and should have oversight from national and local parties, we currently do not have the capacity to provide a meaningful contribution to your account. We hope that for future accounts, the LINK and Marie Curie will be able to establish working relationship early on towards developing the quality accounts.

**A Kinch - Team Leader - LINK Southwark**

## Do you have any comments or questions?

Marie Curie Cancer Care is always keen to receive feedback about our services. If you have any comments or questions about this report please do not hesitate to contact us using the details below:

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Marie Curie Cancer Care provides high quality nursing, totally free, to give people with terminal cancer and other illnesses the choice of dying at home, supported by their families.

[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

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