Quality Account Report 2012/13

Marie Curie Cancer Care

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Chief Executive's Statement

On behalf of Marie Curie Cancer Care it gives me great pleasure to introduce the Annual Quality Account 2012/13 to you.

The Quality Account provides Marie Curie Cancer Care with an opportunity to demonstrate its commitment to quality improvements made through a programme of audit, quality assurance and clinical governance. It describes the quality priorities that we will be focussing on in 2013/14 and provides information on the quality improvements that we have made during 2012/13.

The Account is divided into three domains:

Priority 1 – Patient Experience
Listening to patients and families and engaging Expert Voices in aspects of our strategic development, clinical governance and quality improvements

Priority 2 – Patient Safety
Identifying the risks that have the potential to harm patients and eliminating them through a programme of quality improvement audits

Priority 3 – Clinical Effectiveness
Investing in research, and consistently disseminating results, to ensure that our care is of the highest possible quality

These important areas of care remain the core principles of both our strategic plan and our vision of putting patients and families first.

I am very proud of the reputation that Marie Curie Cancer Care has. Our vision is to provide the best possible care we can and be at the forefront of research and development in end-of-life care. To achieve this we must focus on continual improvement. We will maintain an emphasis on the importance that we put on quality and safety for patients and ensure the culture within the charity supports this and keeps it top of our agenda for 2013/14 and beyond.

We have made excellent progress in 2012 in our ambition for partnership working with other healthcare providers. We continue to work closely with our peers in end-of-life care to develop and share knowledge in palliative care developments.

Of particular note this year is the engagement of patients, carers and volunteers through our Expert Voices programme. I am pleased to say that this is a rapidly developing area which supports our quality improvements, as is shown in many parts of this Quality Account. The use of high-quality, timely information on the quality of care, including qualitative information from complaints and compliments from users, will help to strengthen our clinical governance.

This year's Quality Account sees a shift towards Marie Curie Cancer Care working in a way that allows our outcomes to be measured for a number of projects and initiatives undertaken in 2012. This will continue throughout 2013 when our quality priorities are all aligned to measurable performance indicators ensuring data is consistent, comparable and presents a transparent account of the quality of care provided by Marie Curie.

Another focus for the Marie Curie Cancer Care Quality Account will be recognition of the importance of openness and transparency; this will include the implementation of an adapted Friends and Family Test which can be applied in the context of end-of-life care across our charity, and the requirement for all our staff to speak openly and honestly when things go wrong.

The content of the Quality Account has been endorsed by the Clinical Governance Trustees Committee and comment has been supplied by the Scrutiny Team of the London Borough of Lambeth; Healthwatch Southwark; Mr Brian Andrews, Marie Curie Cancer Care Expert Voice representative; and Lincolnshire West Clinical Commissioning Group. Marie Curie Cancer Care has taken into account feedback given.

I hope you will find our Quality Account informative and helpful in reviewing our progress against our quality priorities for last year and the forthcoming year. I hope it gives you confidence that we are dedicated to ensuring the highest quality of care for all or our patients and their families.

I, Jane Collins, confirm that, to the best of my knowledge, the information in this document is accurate.

JEColl

Chief Executive Dr Jane Collins

Introduction

What is a Quality Account?

A Quality Account is a report that is made available to the public, detailing the quality of services that are being provided by a healthcare organisation. Quality Accounts help to focus the leaders of an organisation on quality improvement and ensure that accountability is taken for providing safe, efficient and effective care for patients.

What is the format of the Marie Curie Cancer Care Quality Account?

Quality Accounts are required to follow the format set out in NHS (2010)- Quality Accounts Regulations. This report will include all mandatory elements required. Where these do not apply to Marie Curie Cancer Care, as a registered charity, this will be stated. This Quality Account Report focuses on Patient Experience (Priority 1), Patient Safety (Priority 2) and Clinical Effectiveness (Priority 3) throughout and is guided by our strategic statement and vision (page six).

It is sectioned as follows:

Section one

- A welcome and statement from the Chief Executive

- Introduction to the report and explanation of content

Section two

- Our quality improvement priorities for 2013/14 – what we plan to do

Section three

- Our services, including Mandatory Statements as required

Section four

- Our quality improvements in 2012/13 – what we have done

Section five

- What others think about Marie Curie Cancer Care's Quality Account

Our vision for 2011/14

Putting patients and families first

We believe that everyone with cancer and other terminal illnesses should have the high-quality care and support that they need at the end of their lives, in the place of their choice. During the first year of our strategy we put in place the building blocks to support the work that will deliver our vision over the following two years.

Putting patients and families first is our core principle. Our strategic plan for 2011/14 sets out our plans to develop, expand and fund our work.

Our 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

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

Quality priorities for 2013/14

How we have decided our quality priorities for the next year

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

The priorities will remain in the domains of Patient Experience (Priority 1), Patient Safety (Priority 2), and Clinical Effectiveness (Priority 3).

Our governance structure

As a charity with a focus on quality, we know that it is important to challenge ourselves to make sure that what we are doing, and plan 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 how we manage the charity to support the quality of care we deliver. To test our existing structure for monitoring and reporting the quality of care, we commissioned an independent audit in 2011. The results of this audit were helpful in identifying areas for improvement and how we could strengthen our governance structures. The recommendations have been implemented. The charity will repeat the audit in 2014 to ensure the actions taken have been effective and to enable us to show continuous quality improvement.

Monitoring progress in 2013/14

The governance structure has been strengthened through the recruitment to a number of key posts within the Quality Assurance team and the introduction of a new reporting structure throughout the charity as detailed on page 9.

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. This will be achieved through the Quality Assurance Framework; identification of risks; clinical audit; and patient, carer and staff feedback.

At a local level the governance structure is maintained and further broken down into areas required for surveillance, maintaining our scrutiny on patient safety, experience and our clinical effectiveness. An example of this can be seen on page 10.

Improving the quality of care

Newly developed clinical policies will support implementation of standards that are focussed on ‘patient outcome’ rather than ‘process standards’.

We are resolute in our aim to collect more meaningful data on incidents and complaints to enable us to target our quality improvement efforts. We will assure this through updated training on our incident reporting system (Sentinel) and implementation of new policy.

Evidence-driven, evidence-generating culture across Marie Curie services

Marie Curie Cancer Care has a particular interest in the potential of research to improve practice in palliative and end-of-life care nationwide. We believe that by investing in high quality palliative care research we can provide immediate and longer-term benefits to people with terminal illnesses towards the end of life.

The integration of research into practice is a vital part of the research pathway. The charity has established a Research From and Into Practice Forum which is supported by a working group who will make the transition from research into care delivery.

Our aim is:

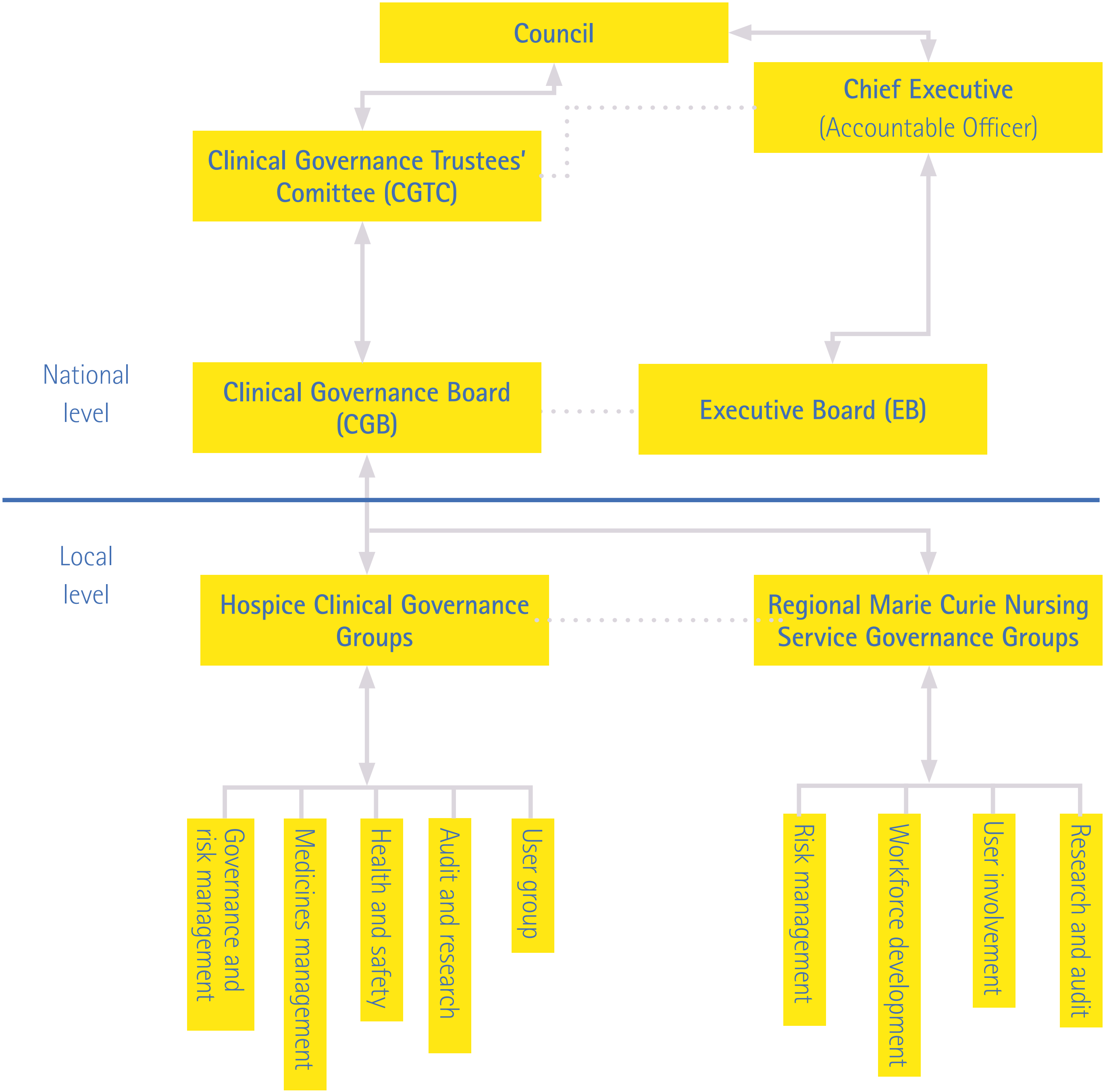
- To fund robust research projects and programmes. To have appropriate processes in place to identify relevant research findings and implement them into practice.

This is further supported by the use of Marie Curie Hospices as hubs: three research facilitators coordinate a portfolio of research studies within the hospices which enable our patients and carers to take part in research studies if they so wish. This ensures our patients receive the highest quality, evidence-based care at the end of life and encourages our clinical staff to develop research skills and maintain the highest standards of evidence-based practice.

The national governance structure

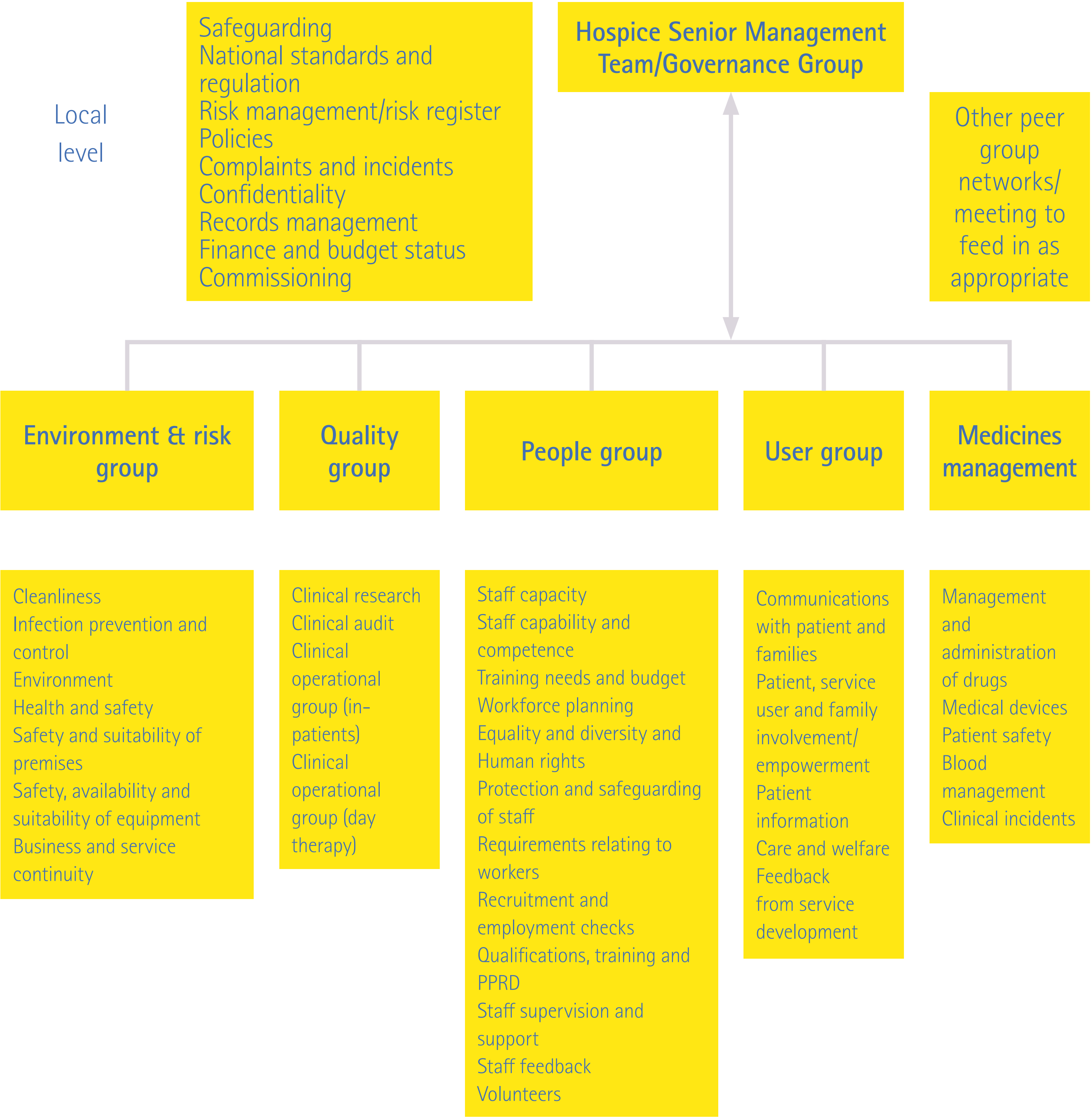
This structure is explicitly defined to ensure that there is continuous monitoring of risk in the charity in a cyclical movement and that the relevant individuals and teams are aware, at any one time, of the requirements for accountability. The Clinical Governance Board reports to a Clinical Governance Trustees Committee (formerly the Caring Services Trustees Committee). Every hospice has its own clinical governance group, and the charity has also introduced clinical governance groups in the Marie Curie Nursing Service for England, Scotland, Wales and Northern Ireland.

Marie Curie Cancer Care – Clinical Governance structure



The national governance structure

This structure demonstrates the breakdown of the governance structure at a local level and ensures the capture of information from key local working groups.



Local level

- Safeguarding
- National standards and regulation
- Risk management/risk register
- Policies
- Complaints and incidents
- Confidentiality
- Records management
- Finance and budget status
- Commissioning

Hospice Senior Management Team/Governance Group

Other peer group networks/ meeting to feed in as appropriate

Environment & risk group

- Cleanliness
- Infection prevention and control
- Environment
- Health and safety
- Safety and suitability of premises
- Safety, availability and suitability of equipment
- Business and service continuity

Quality group

- Clinical research
- Clinical audit
- Clinical operational group (in-patients)
- Clinical operational group (day therapy)

People group

- Staff capacity
- Staff capability and competence
- Training needs and budget
- Workforce planning
- Equality and diversity and Human rights
- Protection and safeguarding of staff
- Requirements relating to workers
- Recruitment and employment checks
- Qualifications, training and PPRD
- Staff supervision and support
- Staff feedback
- Volunteers

User group

- Communications with patient and families
- Patient, service user and family involvement/ empowerment
- Patient information
- Care and welfare
- Feedback from service development

Medicines management

- Management and administration of drugs
- Medical devices
- Patient safety
- Blood management
- Clinical incidents

Patient Experience

Priority 1

By effective analysis and use of patient and family feedback we will improve our services to ensure we meet their needs.

1. Patient and user engagement

Patients and families will help us to define quality and develop new and improved services. We will gather their views in greater numbers; implement changes based on their feedback; and demonstrate that their voice makes a difference to others.

2. Becoming more accessible and providing better care

Through the use of quality indicators for all of our activities in hospices and the Marie Curie Nursing Service we will be able to monitor outcomes and seek continuous improvement. This will enable commissioners to contract our services on behalf of patients with assurance that care is safe, effective and of a high-quality standard.

Our aim is to continuously improve all our services for patients and families.

Our objective is to listen to, analyse, learn, act on and disseminate feedback from patients and carers, both quantitative and qualitative, through a variety of methods. This is then used to improve the quality of services, driven and led by patients, families and carers.

1. Patient and carer engagement

Areas we will report on	What is the current position?
Increase by at least 20% the number of patient and carers feeding back in our yearly surveys.	520 patients and carers were surveyed in 2012.
Provide regular analysis, learning, and dissemination of feedback from the surveys and include the information in patient packs and new digital surveys. There will also be a central space on the website to communicate 'you said, we did'.	New initiative, no current benchmark.
Adapt the Friends and Family Test so that it can be applied in the end-of-life context.	New initiative, no current benchmark adaptation options being reviewed.
Develop new methods for implementation in our services of real-time feedback, based on initiatives such as the pilots commissioned through the National End-of-Life Care Programme.	New initiative, no current benchmark.
Implement the recommendations from the patient and family feedback programme to ensure that we are gathering, analysing and learning from the other significant methods of feedback. We will recruit a senior project manager who will lead on the implementation.	Recruitment in summer 2013.

Establish user-led measurements Patient-reported assessment of symptoms including: • Breathlessness • Bladder and bowels • Pain Patient preferences: • Preferred place of death • Preferred place of care	See Section four.
Develop the Expert Voices (EV) programme so that they are involved in nine internal compliance visits and Patient Led Assessment of Care Environmental (PLACE) audits.	Early stage development. Involvement by two Expert Voices members in March and April 2013.
Include an Expert Voice on the relevant Local Clinical Governance Groups.	In pilot stage at present.
Make readily available information about quality of our services to the public via our website.	Via our website September 2013.

2. Becoming more accessible and providing better care

Areas we will report on	**What is the current position?**
User Involvement User involvement and patient experience groups in the Marie Curie Nursing Service and Marie Curie Hospice services: • Ensure every hospice has a User Involvement and Patient Experience Group that includes patients and carers and feeds into local and national clinical governance groups. • Develop User Involvement groups in the Marie Cure Nursing Service. • Ensure common themes from the groups are reported to the National Clinical Governance Board (CGB).	In early stages of development.
Expert Voices Introduce consultation with the Expert Voices groups of patients and carers with experience of the charity's services. The group will be engaged in the development of the charity's strategy, and its programme, and will be involved in at least 10 pieces of work requiring consultation.	In early stages of development.
Establish user-led measurements Patient-reported assessment of symptoms including: • Breathlessness • Bladder and bowels • Pain Patient preferences: • Preferred place of death • Preferred place of care	See section four.

Engagement of disadvantaged groups Marie Curie Cancer Care is building relationships with Black, Asian and Minority Ethnic (BAME) organisations and other stakeholders working to achieve greater equality of opportunity and reduce disadvantage. It has introduced pilot activity in two hospices to raise awareness of the Marie Curie Nursing Service and hospice services and will measure the following outcomes: • Improve understanding of BAME through research and engagement activities • Identify barriers to meeting needs • Identifiy priorities for policy and service delivery • Increase the number of minority ethnic people accessing Marie Curie services	New initiative, no current benchmark but suitable mechanism for data capture under consideration.
Dementia care Provision of effective end-of-life care for people with dementia (as per NICE Clinical Guideline CG42): • Establish three dementia end-of-life care case managers who will link with dementia care coordinators in the local area • Measure access to and uptake of palliative and end-of-life services by patients with dementia. Report outcomes.	New initiative, no current benchmark but suitable mechanism for data capture under consideration.
Care homes To achieve a reduction in crisis admission to hospital from care homes for patients at end of life. To measure an increase in the use of integrated priorities of care in care homes across Hwyel Dda Health board which covers three counties: Carmarthenshire, Ceredigion and Pembrokeshire (Wales). **Key performance indicators** • The target number of patients in the last weeks of life supported during the first 12 months of operation is 104. • 90% of patients will be on the end-of-life care pathway. • 90% of patients will receive their end-of-life care using the end-of-life care pathway. • 100% of patients cared for will remain in their permanent place of residence (care home). • 90% of patients will be on the service case load for a maximum of seven working days. • 100% of patients who are on the case load for over seven working days will have Delayed Transfers of Care (DTOC) data kept.	New initiative, no current benchmark but suitable mechanism for data capture under consideration.
Marie Curie Helper • By 2014 we will have increased our overall engagement with a rollout of the Marie Curie Helper service to three more sites across the UK, seeing a 75% increase on last year's achievements. • We will conduct a series of in-depth case studies in order to continue to measure the impact the service is having.	Service covering four service areas in 2012. On average, 72% of people rated the service as excellent in 2012.

Choosing where to die Continue to follow the National Preferred Place of Death Audit: 1. The number of deaths recorded electronically per hospice in the year (April to April). 2. The number of patients with a preferred place of death entered electronically.	Data demonstrates a percentage increase year on year to date on average across these standards. See section four.
Programme of work with the Royal College of General Practitioners (RCGP). The aim of the project is to help General Practitioners to improve the care they provide to terminally ill people. The project will work across a number of domains including dementia, Chronic Obstructive Pulmonary Disease (COPD), cancer, and care planning work streams; to embed end-of-life care principles and practices in the College's clinical priorities, eg elderly, dementia, and COPD, to establish a programme of work to improve pain management in end-of-life care. Measures on: 1. Baseline survey of GPs 2. Development of training and resources 3. Dissemination of best practice 4. Collaborating on research	New initiative, no current benchmark.

Patient Safety

Priority 2

Our aim is to ensure that we deliver the safest possible care, with clear knowledge and statement of a quality benchmark. Benchmarking is defined by Camp (1989)[1] simply as,

The search for industry best practice that leads to superior performance.

In other words, benchmarking is a process of finding what best practices are and then proposing what performance should be in the future. For new audit processes this principle will be applied.

Our Objective is to provide 'zero harm' care, demonstrated through the development of a safety thermometer as an improvement tool for measuring, monitoring, analysing and reporting patient harm.

Areas we will report on	**What is the current position?**
Develop a Marie Curie Cancer Care safety thermometer. This will measure key potential patient safety issues or 'harms.'	
Medicines management in hospices Undertake a baseline audit following publication of the Controlled Drug Management Policy using selected accredited tools. Use accredited tools to audit Controlled Drug management in 2013. • The first audit will give a benchmark of practice versus standards. • The second audit will check for improvements in areas identified for improvement. **Medicines management in Marie Curie Nursing Service** There will be an audit of medicines management documentation in the Marie Curie Nursing Service.	New initiative, no current benchmark.
Falls Review and update if necessary the policy for falls management. Undertake a baseline falls audit using national guidelines and best practice principles: • to demonstrate a reduction in incidence of falls • to demonstrate 100% compliance with best practice	Total incidence in 2012/13 (including near misses) = 999.
Pressure ulcers Demonstrate a reduction in incidence and prevalence of pressure ulcers (10% reduction in year) by: • developing a policy for pressure ulcer management • undertaking a baseline pressure ulcer management audit The first audit will benchmark prevalence in May 2013. Thereafter continuous monthly prevalence data will be provided per hospice against the benchmark.	New initiative, no current benchmark. Baseline audit underway.

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[1] Camp, R. 1989. Benchmarking: the Search for Industry Best Practices that Leads to Superior Performance, ASQC Quality Press, Milwaukee, Wisconsin.

Patient Led Assessment of the Care Environment (PLACE) audit Participate in the national PLACE audits (April – June 2013) at all hospices. The set of audits most suited to the hospice environment include: • General organisational questions • Ward and community organisations • External and internal areas • Facilities • Food	New initiative, no current benchmark. Baseline audit underway.
Infection Control Review the current Infection Prevention Policy - We will use selected tools which have been accredited to audit current practice which will: • demonstrate a reduction in the number of hospice acquired infections • record and report all outbreaks of Clostridium difficile and Norovirus.	

Clinical Effectiveness

Priority 3

Our aim is to improve the quality of care delivered to patients and families by ensuring that our research findings directly improve on the care we deliver.

Our objective is to deliver the right care, in the right place, at the right time.

Areas we will report on	**What is the current position?**
Implement and disseminate the most recent findings regarding carers from key research, to ensure that learning is embedded in evidence based practice.	In early stages.
Measure the application of the most recent evidence on effective interventions for support to carers. This will be carried out as part of two carers pilots to be established in 2013.	Pilots report in November 2013.
Carers assessment Explore the use of The Carer Support Needs Assessments Tool developed by the universities of Cambridge and Manchester as a consistent method of identifying the needs of carers.	Early stages of implementation. Pilots in four areas across the UK (including external organisations).
Research Into and From Practice To develop the necessary methodology to translate research into practice to include: • The development of a suite of implementation tools for putting research into practice by The Research into Practice Group. • Linking the outputs from the research into practice work with an audit and patient and carer feedback.	Quarterly working group meetings commence in April 2013.
Audit of symptom management: 1) Breathlessness – awaiting results of a pilot study before progressing Following development of a new Pain Management policy, we will undertake a baseline audit using selected accredited tools. 2a) Pain management (day services in hospices) 2b) Pain management (community – hospice) 2c) Pain management (in-patient – hospice	New initiative, baseline audit underway.

Review of our services

Including Mandatory Statements

During 2012/13 Marie Curie Cancer Care provided services through nine hospices providing care for in-patients, outpatients and day care patients in addition to its community nursing service across the UK.

We have actively engaged in partnership working with a number of other care providers. This has enabled us to make improvements in providing seamless care.

We have created new management and clinical governance structures to respond to the changes in the NHS and to ensure the quality of the care provision for patients. The introduction of the new structures follows the recommendations of an external review commissioned from Mersey Internal Audit Agency (MIAA). In order to ensure continued best practice the review will be repeated in 2014.

The data reviewed for this report has come from a number of Marie Curie services. These services have been developed over a number of years, and we are continually reviewing and creating new services as requested by our service users and their carers. A project is currently underway to review the services we offer to ensure we are meeting patient need.

Governance

Marie Curie Cancer Care's Executive Board, Clinical Governance Board and Clinical Governance Trustees' Committee have reviewed all data available to them on the quality of care in all our services.

All quality data will continue to be formally reviewed quarterly by the Boards and Clinical Governance Trustees' Committee.

Programme of refurbishment at a number of hospices

Minister for Health and Social Services in Wales, Lesley Griffiths AM, officially re-opened the doors of our hospice in Penarth in November 2012, following a £1.7 million refurbishment programme to improve and modernise patient and family facilities. The hospice, formerly known as the Marie Curie Hospice, Penarth has been re-named the Marie Curie Hospice, Cardiff and the Vale to better reflect the area the hospice serves.

Our brand new £15.3 million hospice for the West Midlands was opened in January 2013. The hospice replaces the old Marie Curie Hospice, Solihull, 300 metres away. We also invested around £350,000 in new furniture.

A major refurbishment of the Marie Curie Hospice, Edinburgh was undertaken between May and December 2012. The new-look hospice has more single occupancy rooms, en-suite facilities and a glass-fronted reception area. The improved facilities will provide greater levels of privacy and dignity to patients and their families. Landscaped gardens, fitted external doors to all wards and new balconies on the first floor will also enable people to enjoy the landscaped gardens.

Volunteers

Around 9,000 people volunteer regularly for Marie Curie Cancer Care. A further 25,300 volunteers collect for the Great Daffodil Appeal in March each year. Using volunteers effectively has allowed us to expand our services and help more people at a critical time. We find innovative ways in which to use volunteers in improving our services for families facing end-of-life situations. As a result Marie Curie Cancer Care received the Queen's Diamond Jubilee Volunteering Award in recognition of our contribution to volunteering.

Income generated

The income generated by the NHS services reviewed in 2012/13 represents 100% of the total income generated from the provision of NHS services by Marie Curie Cancer Care for 2012/13.

Services provided by Marie Curie

Marie Curie Hospices	
Glasgow – Scotland	All our hospices provide a range of services including in-patient care, day services and outpatients.
Edinburgh – Scotland	
Belfast – Northern Ireland	
Cardiff and the Vale – Wales	
Liverpool - England	
Newcastle – England	
Bradford – England	
West Midlands – England	
Hampstead – England	

	Marie Curie Nursing Services
Our Marie Curie Nursing Service provides care in the home. Services include planned overnight care, Rapid Response and Multi-visit services depending on what is commissioned by the NHS. In addition, we may provide Discharge Liaison Nurses, as commissioned, to work in hospitals to support the discharge home with care of patients at the end of life. Finally we have a volunteer delivered befriender service, the Marie Curie Helper service, in a small number of regions.	Scotland
	Northern Ireland
	Wales
	North West - England
	North East - England
	Central - England
	London and South East – England
	South West - England
	Eastern - England

Participation in Clinical Audit

A simple definition of a clinical audit is "the comparison of actual practice against agreed, documented, evidence-based standards, with the intention of improving patient care." (Ferris 2002).

Mandatory Statements

During the period from 1 April 2012 to 31 March 2013 there were no national clinical audits or national confidential enquiries that covered NHS services that Marie Curie Cancer Care provides.

During the period from 1 April 2012 to 31 March 2013 there were no national clinical audits or national confidential enquiries which Marie Curie Cancer Care was eligible to participate in.

Marie Curie Cancer Care-wide Audit Programme 2012/13 (hospices)	Data collection period
Medicines management	July 2012
Pain assessment	August 2012
Falls	October 2012
Breathlessness audit	Postponed to allow pilot of new assessment tool

Marie Curie Cancer Care-wide Audit Programme 2012/13 (Marie Curie Nursing Service)	Data collection period
Medicines management re-audit	May 2012
Documentation repeat-audit	October 2012

The results of all these audits are reviewed by the local Clinical Governance Board, and each site produces plans for improvements, where necessary, which are monitored by the Clinical Audit Group and reported to the national Clinical Governance Board.

The end of 2012/2013 has been a time of transition, with a new Clinical Audit Lead coming into post and a pause in Marie Curie wide audit activity taking place, to prepare a revised audit strategy and programme for launch in April 2013. Next year we will have a full programme of Marie Curie wide audits. We will change the focus of audits from process to patient outcomes.

Participation in clinical research

Mandatory Statement

The number of patients and carers receiving NHS services provided or sub-contracted by Marie Curie Cancer Care 2012/13 that were recruited during that period to participate in research approved by a research ethics committee was 312. In addition, a number of Marie Curie hospice staff have been recruited to research studies approved by a research ethics committee or a university ethics committee.

Hospice/Service	Number of patients	Number of carers	Number of staff
Belfast hospice	-	5	20
Bradford hospice	97	-	-
Cardiff and the Vale hospice	-	-	19
Edinburgh hospice	-	3	29
West Midlands hospice	107	43	39
Glasgow hospice	17	-	-
Liverpool hospice	40	-	-
Total	261	51	107

Some examples of our research projects include:

Marie Curie Hospice, Belfast
Identifying vulnerability in grief

Marie Curie Hospice, Glasgow
The European Palliative Care Cancer Symptom Study (EPCCS)

Marie Curie Hospice, Liverpool
Hydration in advanced cancer patients: the testing of a new assessment method

Marie Curie Hospice, West Midlands
Carer Support Needs Assessment Tool (CSNAT)

Investment in palliative and end-of-life care research

Marie Curie 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 made a considerable financial commitment investing £1 million per year into the Marie Curie Cancer Care Research Programme. This funding scheme is open to applications from clinicians and researchers across the UK for research into specific themes with the potential to benefit the care of people at the end of their lives and their carers and families.

We work closely with Cancer Research UK to ensure the funds are allocated using the standards of the Association of Medical Research Charities (AMRC), of which we are a member. Applicants for research projects are asked to demonstrate the potential benefit of the research for patients, their carers and their families.

Research studies are outlined in the report under the domains of Patient Experience, Patient Safety and Clinical Effectiveness. This demonstrates the importance that we put on our research studies being integral to the quality of our services.

Marie Curie Cancer Care continues to support and develop the work of our Palliative Care Research Facilities:

- The Marie Curie Palliative Care Research Unit at University College London

- The Marie Curie Palliative Care Institute Liverpool

- The Marie Curie Palliative Care Research Centre, Cardiff (at the Wales Cancer Trials Unit, Cardiff University)

Marie Curie Palliative Care Research Conference

We continue to hold our annual Marie Curie Palliative Care Research Conference. The aim of the conference is to support the translation of research findings into practice. It is now held jointly with the Royal Society of Medicine, and in 2012 the conference presented the latest evidence from expert researchers and clinicians who work in communities with specific palliative and end-of-life care needs.

Attendees heard about research addressing issues of equality and access for diverse groups of people including lesbian, bisexual, gay and transgender people; people from ethnic minority backgrounds; and people with learning disabilities. More than 200 participants from Marie Curie and other organisations attended to share the latest research and knowledge.

Peer Review

In 2012, 27 peer-reviewed articles resulting from Marie Curie Cancer Care funded research activities were published in key journals. Peer-reviewed articles are evaluated and critiqued by researchers and experts in the same field before the article is published.

Healthcare regulators

We are required to register our services in England with the Care Quality Commission and our current registration status is fully registered. Marie Curie Cancer Care has registration for the following:

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

The 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

We are a national charity and are therefore also registered with the devolved nation's regulators. There is no requirement to report on our services in the devolved countries, although information on all our services in the UK form the basis of this report.

The regulators are tabled below,

Country	**Regulator**
England (hospices and nursing services)	Care Quality Commission (CQC)
Scotland (hospices only)	Healthcare Improvement Scotland (HIS)
Scotland (nursing service only)	Social Care and Social Work Improvement Scotland (SCSWIS)
Wales (hospices only)	Healthcare Inspectorate Wales (HIW)
Wales (nursing service only)	Care and Social Services inspectorate Wales (CSSIW)
Northern Ireland (hospice and nursing service)	Regulation and Quality improvement Authority (RQIA)

All of our services are subject to announced or unannounced inspections at any time. The individual regulators take slightly different approaches to their inspections, hence the report summaries detailed below will vary in style and content.

In 2012 the following compliance inspections were carried out.

Facility	Country	Date	Inspectorate	Announced or unannounced	No. of recommendations made
1. Belfast hospice	Northern Ireland	March 2012	RQIA	Unannounced	Two recommendations
2. Marie Curie Nursing Service England	London Registered Office	June 2012	CQC	Announced	Nil
3. Marie Curie Nursing Service Scotland	Scotland	June 2012	SCSWIS	Announced (short notice)	Nil
4. West Midlands hospice	England	May 2012	CQC	Announced	Nil
5. Liverpool hospice	England	Dec 2012	CQC	Unannounced	Nil
6. Newcastle hospice	England	Jan 2013	CQC	Unannounced	Nil
7. Edinburgh hospice	Scotland	Nov 2012	HIS	Unannounced	Nil
8. Glasgow hospice	Scotland	Aug & Sept 2012	HIS	Unannounced	One recommendation
9. Bradford hospice	England	Jan 2013	CQC	Unannounced	Nil
10. Hampstead hospice	England	March 2013	CQC	Unannounced	Nil
Belfast hospice	Northern Ireland	Feb 2013	RQIA	Self-assessment	-
Marie Curie Nursing Service Wales	Wales	Oct 2012	CSSIW	Self-Assessment	-

Summaries of individual reports are detailed over the next few pages.

1. RQIA at Marie Curie Hospice, Belfast – unannounced March 2012

Staff were observed to attend to patients' needs in a sensitive and caring manner. During the inspection the inspector spoke with two patients and one relative who spoke very positively regarding the facilities, the staff and the quality of care and treatment provided.

Jo Browne RQIA Inspector – March 2012

Recommendations

Number	Regulation Ref	Requirement	Timescale	Details of action taken by registered person(s)
1	28 (1) (d)	The registered manager must ensure all medication incidents are reported **Ref: Standard C23**	Immediately and ongoing	From 17 March 2012 all incidents involving medication are now reported using RQIA Form 1a Statutory Notification of Events (Adult Services).
2	21 (1) (a)	The registered manager must ensure that all issues identified in relation to the care records are addressed as discussed in the main body of the report and during feedback. **Ref: Standard H1**	Immediately and ongoing	New Core Care plans were introduced and were fully implemented by 30 April 2012. An evaluation audit to measure compliance was undertaken in May 2012.

Outcomes achieved following actions:

- We have progressed actions identified by RQIA.
- Updates to Marie Curie's incident reporting system have been undertaken to enable clearer reporting.
- A new Medicines Management Policy has been developed.
- Staff now undertake mandatory medication calculations tests to demonstrate competence.
- All Controlled Drugs are checked by two members of staff to reduce errors (see Section four).
- New core care assessments have been introduced across all Marie Curie Hospices and are subject to continual review and update.

"I could see the room online, before I was admitted, which was reassuring"

Patient, Marie Curie Hospice, Belfast

"Staff are excellent, very friendly"

Patient, Marie Curie Hospice, Belfast

Patient and nurse at Marie Curie Hospice, Belfast

2. CQC review of the Marie Curie Nursing Service, England – announced June 2012

Our current overall judgement is that Marie Curie Nursing and Domiciliary Care Services are meeting all the essential standards of quality and safety inspected, outcomes 01, 04, 07, 14 and 16.

CQC Inspector – June 2012

There were no improvement recommendations made.

Comments made by the inspector:

- We heard from people of the help and support they received to care for unwell relatives. They described as excellent the emotional and practical support received from nurses and healthcare assistants supplied by the Marie Curie Nursing Service.

- A relative described how much she valued the companionship and emotional support received from the Marie Curie Nurse that came three nights a week to her home. She said, "I looked forward to her visits and appreciated the help."

- A person spoken with told us that she was the sole carer for her husband who had a chronic illness, she said, " I was unable to rest at night as I was worried about my husband deteriorating. When we were assigned a Marie Curie Nurse it was a bonus, I felt reassured as I knew he was in safe hands all night."

- District nurses found that Marie Curie Nursing staff were expert at supporting the needs of both the person who was unwell and the people close to them. They helped them to cope with the emotional impact of their illness.

"Over the last 20 years of working in the community I have only experienced an excellent and supportive gold standard service. The Marie Curie staff have always carried out their role in a professional manner with the patient's and family's interests central to the care they provide."

District nurse comment about Marie Curie Nurses

3. SCSWIS review of the Marie Curie Nursing Service, Scotland – announced (short notice) June 2012

The Marie Curie Service is providing very high standards of care and support to people who are nearing the end of life and who wish to remain at home.

SCSWIS Inspector – June 2012

Overall assessment findings

Standard	Grade (June 2012)	Grade (Mar 2012)	Grade (Feb 2012)	Grade (Sept 2010)	Grade (Oct 2009)	Grade (Sept 2008)
Quality of care and support	6- Excellent	Not assessed	Not assessed	6- Excellent	5- Very Good	5- Very Good
Quality of staffing	6- Excellent	Not assessed	Not assessed	Not assessed	5- Very Good	5- Very Good
Quality of management and leadership	6- Excellent	5- Very Good	1- Unsatisfactory	6- Excellent	Not assessed	5- Very Good

NB: The grade of 1– Unsatisfactory for February 2012 was due to a manager missing the deadline for the report and is not related to care or service provision.

There were no improvement recommendations from this inspection in June.

Comment made by the inspector:

- A demonstrable improvement in all areas assessed in 2012.

"Lovely girls; nurses adapted to Dad's changing needs; splendid, all needs being met; would like more shifts."

A carer's comments about Marie Curie Nurses in Scotland

4. CQC inspection of the Marie Curie Hospice, West Midlands England – announced May 2012

The Marie Curie Hospice, West Midlands was meeting all the essential standards of quality and safety inspected meeting outcomes 16, 14, 09, 04 and 01.

CQC inspector – May 2012

There were no improvement recommendations made from this inspection in May 2012.

Comments made to the inspector:

"They have involved me in decisions about how I want to be treated."

Patient, Marie Curie Hospice, West Midlands

"There is a choice of good quality food."

Patient, Marie Curie Hospice, West Midlands

"I have stayed in several hospitals in the last five years, but here I have seen that the patient service is excellent."

Patient, Marie Curie Hospice, West Midlands

"Everyone is so helpful and kind."

Patient, Marie Curie Hospice, West Midlands

"With the help of the kitchen staff I have been able to have food of the consistency that suits me."

Patient, Marie Curie Hospice, West Midlands

"The staff are always patient and nothing seems to get them down."

Patient, Marie Curie Hospice, West Midlands

The new Marie Curie Hospice, West Midlands

The old Marie Curie Hospice, Solihull

The Marie Curie Hospice, Liverpool

5. CQC inspection of the Marie Curie Hospice, Liverpool – unannounced December 2012

The Marie Curie Hospice, Liverpool met all the essential standards of quality and safety inspected, meeting outcomes 16, 14, 09, 04 and 01.

CQC inspector – December 2012

There were no improvement recommendations made from this inspection in December 2012.

Comments made by the inspector:

- The people staying at the hospice told us that they had felt safe there and that they would have felt confident to raise any issues that they had had with staff.
- Staff demonstrated that they had an awareness of safeguarding adults and told us that they would not hesitate to report any safeguarding concerns that arose.
- One of the people staying at the hospice told us that they had observed, "good supervision of staff" and said they had confidence in the knowledge and abilities of the staff supporting them.
- Staff received appropriate professional development. In discussions with staff they told us that they had had an annual appraisal during which they had discussed their training needs. Nurses told us that they had had access to clinical supervision and had attended team meetings.

"They are always popping in. Nothing is too much trouble."

Patient, Marie Curie Hospice, Liverpool

"They go above and beyond."

Patient, Marie Curie Hospice, Liverpool

6. CQC inspection of the Marie Curie Hospice, Newcastle – unannounced January 2012

The Marie Curie Hospice, Newcastle met all the essential standards of quality and safety inspected, meeting outcomes 16, 14, 09, 04 and 01.

CQC inspector – January 2012

There were no improvement recommendations made from this inspection in January 2012.

Comments made by the inspector:

- We observed that people were encouraged to voice their opinions and be involved in how their individual care and treatment was provided. Staff told us, and people confirmed, they would always ask people first before providing care and not automatically assume they wanted help.

- We saw a full assessment was undertaken when a person was admitted, which included nursing and clinical assessments as well as a care assessment. We saw from care records and from talking with people that they were involved in assessments of their needs and care planning.

- We found there were enough qualified, skilled and experienced staff to meet people's needs. People we spoke with were satisfied with the staff providing their care and raised no concerns about staffing levels. One person commented, "The staff are a real nice bunch of people." Another person said, "Staff are respectful, caring and nothing is a problem. They have time to care and reassure us."

- We saw that people who used the service had been asked for their views about their care and treatment and suggestions were acted on. For example provision of a cold drinks machine and more varied food options for people who had special dietary requirements had been introduced following suggestions made by people who used the service.

Regarding the quality of the service one person commented,

"As good as home, care is fantastic, absolutely first class."

Patient, Marie Curie Hospice, Newcastle

The Marie Curie Hospice, Newcastle

7. HIS inspection of the Marie Curie Hospice, Edinburgh – unannounced November 2012

> "The Marie Curie Hospice, Edinburgh - dedicated care and attention is given to people, with particular emphasis on dignity, respect, care, comfort and family support."
>
> **HIS inspector – November 2012**

Work was undertaken on a refurbishment project at the hospice in 2012 to improve the standards of privacy and dignity offered to patients and their families. The in-patient and other services were moved temporarily out of the hospice building to protect service users from construction noise and disruption. During the refurbishment, the service was based at the Western General Hospital, Edinburgh. The in-patient unit had 22 beds offered in single and shared accommodation. All staff from the hospice were moved with the service users. All patients were kept informed about how the changes would affect them and with the plans and information about the move throughout.

The hospice underwent an unannounced inspection whilst it was off site. The purpose of the inspection was to assess the care provided and the environment of the Western General Hospital.

Overall outcome of the inspection:

Quality Theme 1 – Quality of care and support: 4 - Good
Quality Theme 2 – Quality of environment: 4 – Good

Quality Statement Number		Grade (Aug 2012)
1.1	We ensure that people that use this service and carers participate in assessing and improving the quality of the care and support provided by the service.	5- Very Good
1.5	We ensure that our service keeps an accurate up-to-date, comprehensive care record of all aspects of service user care, support and treatment, which reflects individual service user healthcare needs. These records show how we meet service users' physical, psychological, emotional, social and spiritual needs at all times.	4- Good
1.6	We ensure that there is an appropriate risk management system in place, which covers the care, support and treatment delivered within our service and, that it promotes/ maintains the personal safety and security of people who use this service and staff.	4- Good
2.1	We ensure that people that use this service and carers participate in assessing and improving the quality of the environment within the service.	5- Very Good
2.4	We ensure that our infection prevention and control policy and practices, including decontamination, are in line with current legislation and best practice (where appropriate Scottish legislation).	3 - Adequate

NB: to reiterate, the move to Western General Hospital was a temporary measure and the hospice is now back on site in newly refurbished premises which have since been inspected.

Comments by the Inspector:

On the 12 July 2012 inspection, we were told that there had been recent damage to the Western General Hospital building which had significantly disrupted patient care. We were told that the service was experiencing difficulties in getting their landlord to make repairs in a timely fashion. We also saw that some equipment was not working properly. The equipment that was not working could have caused an infection control risk within the unit. This had been reported to the landlord on several occasions, but had not been repaired. As a result of these concerns we made an immediate requirement.

As a result of continued concerns regarding some practice and the cleanliness of the provider Trust environment, the regulator made two immediate requirements.

Actions undertaken

The NHS host hospital received the letter on 23 July 2012 and met the timescale within 24 hours of receipt of the letter. The provider sent information within the prescribed timeframe which satisfied the regulator that the requirements had been met. They sent:

- a copy of the infection control and domestic cleanliness audit, which was carried out by the service manager and infection control advisor

- a list of actions to be taken as a result of the audit

- a cleaning schedule

Other comments by the inspector:

- We found very good evidence that people who use the service and their families participate in assessing and improving the quality of care and support provided by the service. There were a variety of leaflets available which explained what services were available and know what to expect. We found good information on the hospice website about the services offered. There was also information about the temporary accommodation and move to the Western General Hospital.

- User experience groups were held and we saw that they explored a variety of different topics including the hospice refurbishment and feedback letters and suggestions that were made.

- We saw detailed minutes and evidence of action being taken in response to suggestions made. For example the service told us that the times of breakfast had been changed as people who used the service had felt it was served too early.

Reception area of the Marie Curie Hospice, Edinburgh

8. HIS inspection of the Marie Curie Hospice, Glasgow – unannounced August 2012

The Marie Curie Hospice, Glasgow –

We found that people who use the service are complimentary of the service they receive.

HIS inspector – August 2012

Overall Outcome of inspection:

Quality Theme 1 – Quality of care and support: 4 - Good
Quality Theme 3 – Quality of staffing: 3 - Adequate

Quality Statement No.		Grade (Aug 2012)
1.5	We ensure that our service keeps an accurate up-to-date, comprehensive care record of all aspects of service user care, support and treatment, which reflects individual service user healthcare needs. These records show how we meet service users' physical, psychological, emotional, social and spiritual needs at all times.	4- Good
3.1	We ensure that service users and carers participate in assessing and improving the quality of staffing in the service.	5- Very Good
3.2	We are confident that our staff have been recruited and inducted, in a safe and robust manner to protect service users and staff.	3- Adequate
3.3	We have a professional, trained and motivated workforce which operates to National Care Standards, legislation and best practice.	3- Adequate

Comments made by the inspector:

- The hospice has quality assurance systems in place.

- A multidisciplinary approach to care is in place and people using the service have the opportunity to give their opinion to help make improvements.

- People who use the service were encouraged to share their experiences of the service and leaflets entitled 'Tell us what you think' were clearly displayed.

- The leaflet did not make clear that people could take their complaint to the regulatory body.

This inspection resulted in four requirements and one recommendation under the themes of:

- The recording of medication given to people who use the service.

- Improved completion of care plan documentation for all people using the service.

- Significant numbers of clinical staff employed without relevant repeat checks being carried out.

- The provider must also inform Healthcare Improvement Scotland about any allegation of abuse to a service user.

- It was recommended that the Marie Curie Hospice, Glasgow should review complaint information leaflets to guide people appropriately to the regulatory body, Healthcare Improvement Scotland.

9. CQC inspection of the Marie Curie Hospice, Bradford – unannounced February 2013

The Marie Curie Hospice, Bradford met all the essential standards of quality and safety inspected, meeting outcomes 17, 14, 09, 04 and 01.

CQC inspector – February 2013

There were no improvement recommendations made from this inspection in February 2013.

Comments made by the inspector:

- We looked at three patients' records which showed that wherever possible patients and their relatives had been involved in making decisions about their health, personal and social care needs. This demonstrated to us that patients and their representatives had been involved with decisions about care and treatment.

Nurse and patient at the Marie Curie Hospice, Bradford

- We saw the service had a multi-faith room where patients could practice their faith. We talked with two patients who used the day service. They explained how beneficial the art club had been to them, one said it was "wonderful" and the other said if the service was stopped they would miss it.

- Seven patients told us it was the "best care and treatment they had ever received". They explained how, if their care needs changed or if they experienced pain, the staff responded immediately to help them. A relative explained how the staff had provided the specific care their relative needed and how the staff had also offered them support.

- Patients were protected against the risks associated with medicines because the provider had appropriate arrangements in place to manage medicines.

"The service is first class and you cannot surpass it, marvellous."

Patient, Marie Curie Hospice, Bradford

10. CQC inspection of the Marie Curie Hospice, Hampstead– unannounced March 2013

The Marie Curie Hospice, Hampstead met all the essential standards of quality and safety inspected, meeting outcomes 16, 14, 08, 04 and 01.

CQC inspector – March 2013

There were no improvement recommendations made from this inspection in March 2013.
Comments made by the inspector:

- Overall we spoke with 20 patients or their relatives/friends who were visiting, and 10 staff in different areas of the hospice.
- Staff were observed knocking before entering people's rooms and asking before entering curtained off areas.
- Patients stated that when they had to use a call bell nursing staff came to their assistance quickly.
- All bells were placed in reach of people who needed them.
- Information packs were available for each patient and leaflets were available throughout the hospice about services provided and relevant medical conditions.
- Procedures were in place to support people's decisions about resuscitation.

People told us:

"I've been very happy here."

"They are brilliant."

"It's absolutely fantastic."

"You couldn't ask for better."

"Everyone here is brilliant – I can't fault any of them."

"I'm quite satisfied."

"I'd give it five stars."

Nurse and patient at the Marie Curie Hospice, Hampstead

Complaints (2012/13)

Throughout 2012/13 Marie Curie Cancer Care has continued to monitor and act on feedback, both positive and negative from people who use our services.

In addition we have:

- Reviewed and launched two policies (1) Complaints and (2) Incident Reporting and Management.

The launch of these policies has been supported by

- additional training for staff
- a renewed 'tell us what you think' leaflet
- an updated database to ensure that managers follow best practice

Chief Executive, Dr Jane Collins is keen to embed an open and transparent culture in management of complaints and incidents. The new policies and procedures will enable Marie Curie Cancer Care to publish robust data in detail next year.

Data quality – not applicable

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 2012/13 to the Secondary Uses service for inclusion in the Hospital Episode Statistics which are included in the latest published area.

Information Governance Toolkit

The following statement is applicable to Marie Curie Cancer Care. The following statement is required under the Data quality section:

Marie Curie Cancer Care's Information Governance Assessment Report overall score for 2012/13 version 10 was 92% and was graded GREEN: Satisfactory.

Clinical Coding error – not applicable

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 2012/13 by the Audit Commission.

Use of CQINN payment framework – not applicable

The following statement is not applicable to Marie Curie Cancer Care:

Marie Curie Cancer Care income in 2012/13 was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. CQINNs are not currently being applied to our contracts.

Our Quality improvements for 2012/13

How we performed in delivering the quality improvements we set ourselves.

Patient Experience

Priority 1a

1. Patient and carer engagement

National Voices

Our strategic 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 service we offer.

The outcomes that we achieved

- The formation of the Expert Voices Group (EVG) in May 2012 from a group of people with personal experience of caring for someone at the end of life.
- Feedback has been received on a variety of issues either face to face, via email or by telephone depending on both the specific project and the preferences of the individual.
- Engagement of 20 members in the group, eight of whom have used the Marie Curie Nursing Service, six have used Marie Curie Hospices and six used the services of other Specialist Palliative Care providers.
- Representative of diversity in terms of gender, ethnicity, age and sexual orientation.
- Expert Voices Group members have participated in development of the Carers' Strategy

> "Patients and families will help us to define quality and develop new and improved services. We will gather their views in greater numbers; implement changes based on their feedback; and demonstrate that their 'voice' makes a difference to others."
>
> **Marie Curie Strategy 2011**

- Four members of the Expert Voices Group have joined the Patient and Families First Group. This brings services users into the board that will monitor delivery of the patient and family strategy and enable users to directly influence decisions.

- Expert Voices Group members, as well as staff and volunteers from throughout the charity, were invited to share their experiences and give their thoughts on the new In Memory Funds and the best ways to publicise them to families.

- A condolence letter being sent to families of deceased hospice patients was shared with members of the Expert Voices Group for their comments. Feedback was received from five via telephone and email. All comments were collated and a revised version was circulated to the group for final comments.

- Two members of the Expert Voices Group have been invited to join the User Subgroup meetings for Hospices and Nursing Services as part of Clinical Governance Group meetings providing a link to the subgroups

Priority 1b

1. Patient and carer engagement

All of the hospices were asked to focus on making at least four service improvements in 2012 based on feedback from patients and families. This new idea was achieved, and a sample of patient and carer engagements in these improvements, from each hospice, is detailed below in the format of 'you said', 'we did' and the outcome.

Marie Curie Hospice, Cardiff and the Vale

You said	We did	Outcome
We would like some help with information regarding welfare benefits.	The Social Workers in the hospice undertook training to update.	Assistance is now given on all benefits available and organisations that can help.

Marie Curie Hospice, Hampstead

You said	We did	Outcome
We would prefer to have blood transfusions as a day case.	We introduced blood transfusion clinics into the day unit.	This enabled you to go home each day and freed up bed space on the wards for other patients to be admitted.

Marie Curie Hospice, Bradford

You said	We did	Outcome
Can I drive when taking strong pain killers, is there a leaflet to explain this?	We reviewed the Marie Curie leaflet and discussed it with other palliative care providers in the region.	We made available an updated leaflet for all patients in the region with advice on driving whilst taking strong pain killers.

Marie Curie Hospice, Belfast

You said	We did	Outcome
We want to change the focus and content of the memorial service for bereaved relatives.	We invited you to a focus group to hear your views.	We listened to your views and recommendations and the event, which will now be called 'Celebration of Life', will take place every spring from 2013.

Marie Curie Hospice, Edinburgh

You said	We did	Outcome
En-suite shower rooms would be much more dignified than having to go across a hallway.	All rooms now have en-suites, improving patient privacy and dignity.	We redesigned patients' rooms to incorporate en-suites as part of our refurbishment.

Marie Curie Hospice, Liverpool

You said	We did	Outcome
We would like the bereaved parents group to continue, to have meetings in the hospice, and to allow new members to join when they were ready.	We allocated a trained and supervised volunteer to support the group.	The bereaved parents group will continue to run in the hospice so bereaved parents can share their experiences and support each other.

Marie Curie Hospice, Glasgow

You said	We did	Outcome
We were not clear about our policy on the in-patient unit for open visiting, or for overnight stays for relatives/close friends.	We amended the local information leaflet to clearly state that we welcome open visiting and requests to stay overnight, and made sure that staff were aware of this.	Family members and friends of patients can now see our position on these important issues in writing, and are aware that their requests to spend more time at the hospice will be welcomed.

Marie Curie Hospice, Newcastle

You said	We did	Outcome
You would like to have access to a trolley service.	We introduced a sweet and drink trolley, available at reception and regularly taken to in-patients and the day hospice	Snacks are available to patients and relatives whenever they are required.

Marie Curie Hospice, West Midlands

You said	We did	Outcome
We would like to learn some exercises suitable for us.	We introduced an exercise class, showing patients exercises that they can also do at home.	This is helping patients considerably with their mobility.

Allied Healthcare professionals, including occupational therapists, social workers, chaplain and doctors

Bradford Hospice Occupational Therapists

You said	We did	Outcome
The service for motor neurone disease patients is too fragmented between different rehab teams.	We set up meetings with our neuro outreach team to discuss the needs of motor neurone disease patients and develop joint working. We are starting to develop a joint clinic at the hospice.	More joint working is leading to a more seamless service for motor neurone disease patients. Referrals to Day Therapy have increased.

Cardiff and the Vale Hospice Allied Health Professionals (AHP)

You said	We did	Outcome
We want to learn some relaxation techniques in the day service.	We developed a programme coordinated by AHPs and volunteer therapists to support sessions such as yoga, breathing and general relaxation.	Patients learn ways in which to relax which helps them to manage day to day issues which sometimes feel overwhelming.

Consultant in Palliative Care Bradford Hospice

You said	We did	Outcome
There are significant waiting times to access the *Breathe Better Programme.*	We changed the programme so that patients can join at any point, rather than waiting for the next cohort to start and risking the possibility of being too poorly to attend.	Patients can start straight away and benefit from the programme.

Priority 1c

1. Patient and carer engagement

National users survey

Following the 2011 user survey, Marie Curie Cancer Care commissioned an external company to examine the current system of surveying patients and families in order to determine whether we are using the most appropriate mechanism to gather patients' and families' views. We also wanted to ensure that we are not only gathering feedback but that, more importantly, this feedback is having an impact on how we deliver our care.

Outcomes achieved

- We have devised an in-patient survey - a paper questionnaire that patients are able to either complete themselves or with the assistance of a volunteer.

- We have developed separate questionnaires to be completed by patients or carers of each of the patient groups (Marie Curie Nursing Service patients, hospice in-patients and hospice community and outpatients).

- We have added new questions asking:
    - whether the nurse treated the patient with dignity and respect
    - about the welcome provided to people when they first use the hospice
    - about the quality of information provided by Marie Curie

- Hospice in-patients were not excluded from the survey even if they were assessed as approaching death or had a deteriorating health status. However, the number of patients at this stage unable to participate is recorded along with the reasons for exclusion in a consistent format between hospices.

- The number of patients and carers spoken to by our team of corporate volunteers increased as they were contacting hospice outpatients, day therapy users and community patients by telephone.

> "It didn't inconvenience me in any way and I feel it was worthwhile. If, by my helping, it releases the Marie Curie staff to get on with what they do best, caring for the ill and infirm and to improve this process, I feel it was worth it. "

Marie Curie volunteer who helped with the survey

National users survey results 2012

As in 2011, the in-patient surveys were administered by volunteers recruited and trained by the hospices. We encouraged 520 patients and carers to self-complete the paper surveys where possible.

Again the results were extremely positive, and most importantly 98% of Marie Curie Nursing Service patients, 100% of hospice community patients, 99% of day therapy patients and 98% of in-patients rated their overall experience of Marie Curie Cancer Care as very good or excellent.

Based on a response of 'very good' or 'excellent'

Measure	Nursing Service		Community		Day therapy		In-patients	
	2011	2012	2011	2012	2011	2012	2011	2012
Relief of pain	86%	91%	89%	92%	81%	100%	79%	97%
Relief of other symptoms	81%	96%	85%	93%	78%	99%	74%	97%
Emotional support	86%	93%	90%	94%	84%	95%	76%	96%
Spiritual support	79%	94%	76%	96%	76%	92%	31%	94%
Treated with dignity and respect	–	94%	–	92%	–	98%	–	88%
Information provided was good or very good	–	96%	–	–	–	–	–	90%
Welcome was either good or very good	–	–	–	–	–	97%	–	97%

> "All my stays at Marie Curie have been completely different from my stays at hospital. At Marie Curie everyone nurses you, but they all have time for every little problem at night. They give a wonderful service and give you the will to want to live."

Patient at the Marie Curie Hospice, West Midlands

> "It would be impossible to improve on the care and support both my husband and I have received while my husband has been in the hospice."

Carer of a patient in the Marie Curie Hospice, Cardiff and the Vale

Priority 1d

2. Becoming more accessible and providing better care

Rapid Response Service Lincolnshire

The Marie Curie Rapid Response Service (RRS) in Lincolnshire is a crisis response nursing service provided by Marie Curie Cancer Care on behalf of NHS Lincolnshire. It aims to provide palliative and end-of-life patients and families access to the service directly via a single point of access on an as and when basis during out of hours. The Rapid Response Registered Nurses and Healthcare Assistants visit patients in their own homes or normal place of residence (eg care home) or provide phone support where appropriate, prioritising patients based on need.

On average the service receives 580 referrals per month and provides care to more than 200 patients, 100 of whom access the service for the first time.

The outcomes we achieved

- An increase in the use of the service

- Of the 580 referrals received each month, less than 1% require readmission to hospital

- Maximisation of capacity and resources by dealing with multiple patients per shift

Marie Curie Rapid Response Nurse

> "The support that you provided enabled Julie to stay, as she wished, in her own home, surrounded by her family until the very end. They made every effort to ensure she was as comfortable as possible; the nurses always had time to "chat", putting both Julie and ourselves at ease."
>
> **Relative of a patient**

Priority 1e

2. Becoming more accessible and providing better care

Derbyshire – working in partnership

The Marie Curie Self-referral pilot project, launched on 18 April 2011, ran throughout 2012. The pilot allowed Derbyshire residents who were approaching end of life and who were not currently under the regular care of a district nurse to approach Marie Curie directly for an assessment of their eligibility to receive Marie Curie nursing care. If they met the eligibility criteria, Marie Curie nursing care was provided in the home.

Aim of the project

To determine whether self-referral could make measurable improvements for patients such as increasing choice and equity of access, and providing care to those who may not have otherwise received support.

The objective

To explore the acceptability of self-referral to patients and families, medical professionals and commissioners.

Outcomes of the project

Referrals were accepted from patients, carers, and healthcare professionals (with the exception of district nurses). To receive care patients needed to meet the following criteria of:

- not having a district nurse actively involved in their care

- being over the age of 18

- being in the last year of life

- being willing to allow the Marie Curie Nursing Service to share medical information with their primary care team

Despite extensive publicity of the project and engagement with the community at large, only 50 referrals in total were received during the two years. Of these only three went on to receive nursing care from Marie Curie without referral from a healthcare professional. A further 15 patients also received our care but these were referred from their district nurse after a conversation was had with them on behalf of the patient.

The main things we learned from this project was that not many people are coming forward to self-refer to the service, and that the majority of people contacting us wanted information and help with liaising with other healthcare professionals. People contacting the self-referral line were already reasonably well-linked with the appropriate professionals, but may not have realised it.

The decision has been made to not offer this service but to explore others ways of opening up our services to provide care to those who may not otherwise receive support.

Priority 1f

2. Becoming more accessible and providing better care

Derbyshire – training for carers

Marie Curie Cancer Care has developed training sessions for carers to provide information, education and support for those caring for someone at the end of life. We used some of the money allocated to the Derbyshire self referral project to undertake a series of workshops on raising awareness of end of life, focusing on the needs of people with long term conditions and their carers as they move towards the need for palliative care at the end of life. The work was carried out in partnership with local health and social care services, the local commissioning board in Derby, and Derbyshire Carers Association.

We have piloted an interactive programme of support, guidance, information and advice to carers in preparation for the support they may need when caring for someone towards the end of life. Issues identified by carers as important elements of support include: preparing decisions ahead; preferred place of death; pre-bereavement and post-bereavement support; personalised information; emergency contacts; advance care plans; funerals; Wills; and welfare guardianship. The work consists of putting on seminars and workshops for carers based on the national Caring with Confidence programme, linked to the Dippex, Health Talk Online. Further information can be found via the links below:

nhs.uk/carersdirect
healthtalkonline.org/dyingandbereavement/caringforsomeonewithterminalillness

Our aim is to:

- Work with the Derbyshire Commissioning Board and specifically with Derbyshire Carers Association to introduce training for carers in Derby and across the county.

Our objectives are to:

- Help prevent carer ill-health, so reducing the burden on the NHS

- Help prevent carer breakdown, so reducing the need for care provided by social services

- Help carers and patients at the end of life achieve patients' preferred place of care and death, which we know to usually be in their own homes, so reducing emergency admissions, and ensuring that hospital beds and other NHS facilities can be used for active interventions

Outcomes:

- We have undertaken four workshops in the city and county.

- We have raised awareness of the issues of death and dying for people with long term conditions and their carers.

- We have supported carers with information and education on caring at the end of life, including becoming a carer, the external support available, the impact of caring and making advanced plans for the end of life.

- We have reached out to excluded Black Asian and Minority Asian (BAME) communities.

Priority 1g

2. Becoming more accessible and providing better care

Black Asian and Minority Ethnic (BAME) and disadvantaged communities – patients at the end of life and their carers

In 2012 Marie Curie Cancer Care looked at how we could improve our services to patients towards the end of their lives and their carers from BAME and other potentially excluded communities. A proposal outlining ideas for future actions was submitted to the charity's Council of Trustees for approval. The Council agreed to recruit a Senior Project Manager (Diversity), which we did in November 2012, to work on the equality and diversity of our services and ensure access to disadvantaged groups. Guidance for the new Equality Act 2010 sets out nine protected characteristics and states:

Voluntary and community sector providers of services may wish to consider whether there are any groups that are not well represented among your service users as they should be and if so consider whether you could use positive action to encourage them to use your organisation more.

The National Institute for Health and Clinical Excellence (NICE) in its new Quality Standard for End-of-Life Care states that:

People approaching the end of life and their families and carers should have access to the high-quality care described in this quality standard on the basis of need and that takes into account their preferences, regardless of their individual circumstances.

Our aim is to:

- Build on what we know from the work we have carried out already on engaging excluded groups through the Marie Curie Delivering Choice Programme in Leeds, the work in Bradford and the prospective work in Cardiff and the Vale

Our objectives are to:

- Map and scope the needs of the BAME and disadvantaged communities, identifying gaps and establishing priorities, whilst also taking into account demographic trends for the future

- Build up key external partnerships, both national and regional

- Design and develop pragmatic support services which will address the present and future needs of the groups and establish best practice that will be embedded in our services

Priority 1h

2. Becoming more accessible and providing better care

Coordination Centre South of Tyne and Wear single point of access

The End-of-Life Care Coordination Centre acts as a single point of access for organising a variety of services including packages of care, information on services, and management information on demand and capacity of services. It ensures equity of access to services, equity of available services, and value for money. The centre is also responsible for the maintenance of a locality palliative care register. The service was set up as an outcome of the Marie Curie Delivering Choice Programme in South of Tyne and Wear.

Our aim:

- To improve the coordination and provision of packages of care for patients at the end of life and their families to enable them to be cared for and die in the place of their choice.

Our objectives:

- To improve the organisation and coordination of packages of care to improve discharge processes and community care, potentially reducing hospital admissions and length of stay.

- To provide a central point of communication about care packages for professionals, patients their families and carers.

- To reduce the amount of time spent by clinical staff organising packages of care, allowing time to be spent on the delivery of clinical care.

- To improve continuity of care through a coordinated approach to provision.

- To provide equity in the booking of care packages across all professional groups.

- To promote integrated working across health and social care professionals.

- To coordinate funding of palliative services and end-of-life providers, ensuring that available resources and demand are optimised.

- To effectively manage resources to ensure appropriate risk management, equity of available services, equity of access to services and value for money.

- To maintain a locality-wide palliative care register.

- To provide information and signposting to services to professionals.

- To provide management information related to demand for care and unmet need.

Outcomes:

All objectives were met for this project.

Priority 1i

2. Becoming more accessible and providing better care

Marie Curie Helper service

The Marie Curie Helper service relies on trained volunteers who offer support to people with a terminal illness and/ or carers in Somerset, Bristol, Nottinghamshire, Liverpool and East London.

Aims of the service

To develop a relationship over a period of time based on trust, confidentiality, emotional and practical support. This is highly valued by those already receiving the service, leading to significant improvements in emotional health and mental wellbeing for both the terminally ill person and their carers.

As part of the ongoing review of the support provided by the Marie Curie Helper service, satisfaction surveys are sent to the person in receipt of the service. This can either be the terminally ill person or the carer. The survey is sent out approximately six weeks following the assignment with a volunteer and after a minimum of four visits.

Outcomes of the service delivery

- Between November 2011 and December 2012, 28 terminally ill people and 12 carers took part in the survey.

- Across all four service areas 71% of terminally ill people and 75% of carers rated the Helper service as providing them with 'excellent' support overall.

- 21% of terminally ill people and 17% of carers rated the Helper service as providing them with 'very good' support overall. The support provided included emotional support, practical support, companionship and information about other services.

In addition, having a break from caring is essential to ensuring a carer can cope. Of those who returned the satisfaction questionnaire:

- 70% of carers stated that the service **'always'** enables them to have a break from their caring role.

Priority 1j

2. Becoming more accessible and providing better care

Working in partnership – St. Joseph's Hospice

We have hosted a number of joint workshops and raised the profile of Marie Curie Cancer Care across East London. We also run the Marie Curie Helper service from St. Joseph's Hospice.

Our aim is to:

- develop a strategic partnership with St Joseph's and to work collaboratively to provide leadership that drives improvement in the commissioning, design and delivery of care

Our objective was to:

- become known and understood

- be perceived as leaders in end-of-life care

- improve the coordination of care, and explore options to enhance support for families and carers

Outcomes:

- A service development partnership agreement has been signed.

- We have delivered a number of stakeholder workshops to raise awareness of local end-of-life care needs and challenges.

- We are exploring the feasibility and design of an East London coordination centre to improve end-of-life care outcomes and improve efficiency.

- The overall partnership provides leadership and a vehicle for change across East London, ie working collaboratively to lead service improvements.

Priority 1k

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2. Becoming more accessible and providing better care

Working in partnership – St Mungo's

St Mungo's is a leading homelessness charity in London and the south of England. Established 40 years ago, it runs approximately 100 housing, health and work-related projects. Each night it provides accommodation for up to 1,500 people who would otherwise be homeless, or at risk of homelessness.

In 2008 St Mungo's initiated a partnership with Marie Curie and launched its service in March 2009.

Our aim:

- To launch the UK's first palliative care service for homeless people facing end-of-life issues.

Our objectives:

- To provide end-of-life support to clients, residents and staff.

- To develop good working relationships with other end-of-life care providers.

- To provide training and awareness.

Outcomes:

- We raised the profile of end-of-life care needs of people who are homeless, creating a network of other homeless charities who are now more aware of end-of-life issues.

- We identified referral guidelines for staff at St Mungo's to use to refer their clients to the palliative care service run at St Mungo's.

- We provided a flexible and responsive care pathway to support a diverse range of clients.

- We provided staff training and awareness of the service and end-of-life care issues. St Mungo's offered support from their palliative care coordinator.

- Key areas of concern have been identified:

    – Liver disease and the lack of information surrounding what end stage liver disease looks like, so that hostel staff can tell when a client is deteriorating.

    – Bereavement/impact of sudden death

    – Impact of complex need

- More than 100 residents received one-to-one support

- It is felt that more residents are residing longer at home* than previously achieved (no data available yet).

- There has been an increase in the number of planned deaths at home*.

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* Home is considered to be their usual place of residence (eg the hostel they were living in).

- More than 70 projects received direct support and advice.
- More than 200 frontline staff received end-of-life care training.
- Training was extended to external homelessness agencies in 2011.
- There is raised awareness of issues relating to end of life and homelessness, and resources include a DVD, information booklets and an interactive resource pack.
- A working group has been set up to share best practice.
- There are improved communications with primary and secondary care services about residents' needs.

Award

The project, run in partnership by St Mungo's and Marie Curie to improve end-of-life care for homeless people, was commended at the Andy Ludlow Homelessness Awards. It was placed in the top six of 50 entries. Colleagues from St Mungo's and Marie Curie attended the awards ceremony at Speaker's House in the House of Commons.

Colleagues from St Mungo's and Marie Curie at the awards ceremony at Speaker's House in the House of Commons.

For more information about the project, contact:

St Mungo's
endoflifecare@mungos.org

mungos.org/endoflifecare

Marie Curie Cancer Care
mariecurie.org.uk/stmungos

Priority 1l

2. Becoming more accessible and providing better care

Palliative and end-of-life care research (1)

As part of our investment in palliative and end-of-life care research, Marie Curie funds a number of studies that aim to improve patients' and carers' experiences at the end of life. If studies involve the recruitment of participants, they are included in the National Institute of Health Research Clinical Research Network (NIHR CRN) Portfolio and so have access to NHS infrastructure (eg research staff, facilities, assistance with patient recruitment) to support the research project. Ongoing studies are shown in the table below together with their recruitment figures for 2012/13.

Research study	**Number of participants recruited between April 2012 and March 2013**
Dr Anthony Byrne, A study of the care needs of Idiopathic Pulmonary Fibrosis (IPF) patients and their carers	22 patients, 16 carers
Dr Christine Campbell, Identifying patients who would benefit from palliative care, irrespective of diagnosis: the development and feasibility testing of a primary care-based intervention	Six patients and carers, 21 healthcare professionals
Dr Maureen Coombs and Professor Alison Richardson, An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice	Eight patients and relatives, 214 healthcare professionals
Dr Morag Farquhar, End-of-life care in advanced Chronic Obstructive Pulmonary Disease (COPD): identifying, understanding and meeting the changing care and support needs of patients and their carers	210 patients, 25 carers, three healthcare professionals
Dr Debra Howell, University of York, Exploration of factors associated with place of care and place of death in patients with haematological malignancies	260 patients, one carer, 25 healthcare professionals
Dr Louise Jones, Marie Curie Palliative Care Research Unit, UCL The CoMPASs:IOn Programme (Care Of Memory Problems in Advanced Stages: Improving Our Knowledge)	42 patients, 32 carers, 87 healthcare professionals
Mr Nick Ockenden and Professor Sheila Payne, Volunteer management in palliative care - meeting the specific challenges of involving volunteers in palliative care roles which require direct contact with patients or their families	29 patients, 14 carers, 72 healthcare professionals
Professor Scott Murray, A feasibility study of early identification, assessment and support for informal carers in primary care	Two patients, 16 carers
Professor Sheila Payne, Lancaster University, 'Unpacking the home': family carers' reflections on dying at home	59 carers

Patient Safety

Priority 2a

Infection Prevention and Control

In 2012 Marie Curie Cancer Care undertook the second national audit of infection control. The audit focussed on the care environment and patient areas.

The audit tool used was adapted from the Infection Prevention Society (formerly Infection Control Nurses Association) audit tool to measure compliance to the following standard; All (100%) Marie Curie hospices will provide and maintain a clean environment that facilitates the prevention and control of infections.

NB: There is an overarching policy in Wales relating to the Cardiff and the Vale (Penarth) hospice referring to infection control standards, which includes standards for the environment. Glasgow hospice maintains infection control governance and policy compliance via the NHS Greater Glasgow & Clyde health board 'Prevention and Control of Infection' manual. Neither hospice therefore uses the afore mentioned audit tool which gives rise to N/A 22% on some aspects of the audit results.

Outcomes we achieved

- All hospices have an infection control link nurse working in partnership with their NHS colleagues.

- All hospices have service level agreements in place with local NHS trusts, enhancing our partnership working.

- All hospices have hand hygiene audits in place.

Actions taken

- Staff at Edinburgh hospice have introduced a tagging system to demonstrate that equipment has been cleaned.

- Staff at Glasgow hospice complete daily cleaning check lists which are renewed every week and retained for auditing purposes.

- Staff at Belfast hospice have a comprehensive weekly cleaning schedule that must be signed off when equipment is cleaned or replaced.

"It is very clean, the housekeepers are excellent.

Patient, Marie Curie Hospice, Belfast

Infection control audit for 2012	**Yes**	**No**	**N/A**
Does the hospice have access to the NHS document 'Infection Control in the Built Environment?'	**78%**	**-**	**22%**
Does the hospice have comprehensive procedures based on the following documents; 'Revised Guidance for Contract Cleaning', 'National Specifications for Cleanliness', 'Revised Healthcare Cleaning Manual'?	**78%**	**-**	**22%**
Does the hospice have a procedure in place for regular decontamination of curtains and blinds?	**100%**	**-**	**-**
Does the hospice have structures in place to ensure distribution, compliance and auditing of cleanliness?	**100%**	**-**	**-**

Total percentage of the areas audited that were deemed to be visibly clean, and in a good state of repair/ working order and made of impermeable/ washable materials	**% Compliance 2012**
Belfast	**100%**
Bradford	**99%**
Edinburgh	**97%**
Glasgow	**97%**
Hampstead	**100%**
Liverpool	**99%**
Newcastle	**99%**
Cardiff and the Vale	**99%**
West Midlands	**95%**

How we supported these improvements

- We have a mandatory training programme for infection control.
- We have trained infection control link nurses in each hospice.
- We have service level agreements with the NHS infection control teams to support hospice staff with expert advice.

Priority 2b

Medicines management

In July 2012 the Quality Assurance Team carried out a broad audit of medicine management standards. From this, new medicine and controlled drug policies were developed in February 2013 which, alongside new standard operating procedures, form part of a full suite of medicine management policy.

Standard	**2011**	**2012**
Standard 1: The process of prescribing, ordering, dispensing, transport, receipt, storage, documentation, administration and destruction of medicines should be in accordance with national and local guidance.	**95%**	**95%**
Standard 2: All controlled stationery used to prescribe and order medicines must be ordered and secured securely.	**91%**	**96%**
Standard 3: Use of unlicensed medicines and licensed medicines outside the manufacturer's license, should be explicit and follow national and professional guidance.	**44%**	**63%**
Standard 4: All practitioners that administer drugs should have undertaken a competency based assessment by a senior nurse, manager, pharmacist or consultant at induction and provide documented evidence.	**44%**	**89%**
Standard 5: Systems should be in place to identify and learn from incidents and adverse events and shared across the charity. *An additional question was asked under this standard in 2012, so this is not a direct comparison.	**89%**	**83%**
Standard 6: Procedures should be established and maintained to ensure the prompt reporting of adverse incidents relating to medical devices.	**100%**	**100%**

Medication incidents

The professional development team has introduced drug calculation testing for all staff (including agency and bank nurses). Staff cannot administer drugs unless they have passed the drug calculation test introduced in 2012.

All controlled drug administration is undertaken by two nurses at all times.

Outcomes we achieved:

- All nursing staff have to undertake a drug calculation test before being allowed to do medication rounds.

- All nursing and medical staff have to undertake an annual calculation test.

- There has been an increase in the number of staff undertaking medicine calculation training.

- Increased numbers of staff have completed and passed a medicine calculation test.

- Any issues in relation to medicines are discussed at weekly multidisciplinary team meetings.

- There has been increased use of the Sentinel system to report and record medicine errors.

- Reporting of errors can be made via the Sentinel system.

Medication incidents	**Q1 2012/13**	**Q2 2012/13**	**Q3 2012/13**	**Q4 2012/13**
Hospices	149	209	151	72
Nursing regions	11	20	31	9

Online drug calculation tests 2012	**Number of staff**	**Comment**
Total undertaken	714	
Pass on first attempt	618/714	Three people who failed the first attempt did not have a second attempt.
Pass on second attempt	141/193	61 people failed the second attempt.
Pass on third attempt	39/40	21 who failed the second attempt did not have a third attempt.

How we supported these improvements

- We have introduced a new medicines management policy which includes standard operating procedures to support staff.

- We have encouraged the implementation of a process to embed new policy for staff so that they are fully aware of new guidance.

- We monitor risk through a Clinical Governance Board and identify themes through incident management.

- We have introduced new medicines management training.

- We have introduced mandatory drug calculation testing which can be done online for ease and speed of access for new staff.

- We have introduced a 'no interruption' policy to support staff when they are giving out medicines.

- We are funding a research project led by Mr Andrew Dickman at the University of Liverpool, investigating the compatibility of combinations of drugs given to manage symptoms at the end of life - ChemdEL: chemical compatibility of drugs administered by continuous subcutaneous infusion for end-of-life care.

Priority 2c

Availability of patient notes in the home for the Marie Curie Nursing Service

Up to date available records are important to inform our staff of the patient's current clinical condition and any preferences they have about their care. The records are vital to ensuring patient safety and good continuity of care. Previous audits by Marie Curie Cancer Care have shown that on occasion key elements of community services records are missing, such as risk assessment and care plans. This means that the Marie Curie Nurse has to contact district nurses, often out of hours, and ask for information.

In 2012 a Clinical Lead Nurse role was introduced in order to carry out the assessments ourselves, documenting key assessments that the Marie Curie Nurse requires to carry out safe and effective practice.

The availability of patient notes in the home was audited in September 2011 and again in October 2012.

Our aim:

- To ensure that there is smooth transition of care planning between providers that enables the provision of safe and high-quality patient care.

Our objectives:

- To encourage staff to report when notes were unavailable and to take proactive action.

- To increase the availability of patients' records in the home.

- To ensure the provision of accurate and relevant information within the patient notes.

Outcomes we achieved

- In October 2012 there was a 10% increase in the number of responses we had from staff auditing the availability of notes in the patient's home.

- In 2011 98% of patients audited had notes available in the home; in 2012 this remained the same at 98%.

- However the number of notes containing the current relevant information increased from 95% to 96%.

- The number of staff taking proactive action when notes were unavailable, contacting the primary care team and using the paperwork developed by Marie Curie to ensure we capture care given, rose from 53% to 64%.

- Single episode of care documents are now carried by Marie Curie Nurses.

Priority 2d

Increasing effective partnership working

Darlington Community Palliative Rapid Response Team 24/7

The Darlington Community Palliative Rapid Response Service was developed in line with the 2008 National End-of-Life Care Strategy and NHS County Durham and Darlington's Five year Strategy (2009-14). Delivered in partnership by St Teresa's Hospice, Darlington and Marie Curie Cancer Care, the service provides high-quality, flexible and responsive palliative nursing interventions at short notice. The service has a one hour response target for unplanned interventions but can also deliver planned support for short periods.

The Partnership Steering Group monitors activity and oversees strategic and governance issues: particular emphasis has been placed in the initial six months into improving links with local GPs and district nursing teams with significant improvement noted in communication through partnership working. During this period no complaints or serious incidents were recorded.

The aims of the service

To enable people to be cared for and die in their preferred place, to reduce avoidable crisis hospital admissions and to facilitate rapid discharge. The service is operational 24 hours per day with a Marie Curie Registered Nurse and a St Teresa's Healthcare Assistant on duty at all times. In addition, a senior registered nurse manages the staff on a daily basis, provides liaison with other health professionals and clinical supervision.

Outcomes we have achieved

- Between 1 September 2011 and 31 March 2012, the service provided support to 50 patients (of which 74% had cancer), delivering over 180 interventions.

- The principal sources of referral were district nursing (35%), care home staff (16%) and St Teresa's in-patient unit (16%).

- In every case the service met the one hour response target (100%).

- At referral only 16% of patients had an Advanced Care Plan (ACP) in place or Do Not Attempt Resuscitation (DNAR) status recorded – these gaps were addressed during or following the team's intervention.

- 33 patients supported at home would otherwise have been admitted to hospital.

- A clear reduction in stress and anxiety for patients and carers was evidenced by supportive comments.

> Family had commented to another service provider that they had found the Rapid Response team to be "an invaluable service" and felt very supported.
>
> **A family receiving the Rapid Response Service.**

> Patient stated she was going to call an ambulance but decided to try us first. Patient said she wanted to remain at home and was grateful we helped her to do so.
>
> **Patient in the care of the Rapid Response Service.**

> Contacted by GP Dr Nevison who thanked us for our input.
>
> **GP working in partnership with the Rapid Response Service.**

Clinical Effectiveness

Priority 3a

Research into palliative and end-of-life care

As part of our investment in palliative and end-of-life care research, Marie Curie funds a number of studies that aim to improve clinical effectiveness. All such studies are included in the National Institute of Health Research Clinical Research Network (NIHR CRN) Portfolio and so have access to NHS infrastructure (eg research staff, facilities, assistance with patient recruitment) to support the research project. The aim of all Marie Curie funded research is to directly influence improvements in the quality of life of patients and carers.

The following ongoing research studies are aligned to our intentions to improve upon clinical effectiveness in palliative and end-of-life care.

Research study	**Number of participants recruited between April 2012 and March 2013**
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	40 patients
Professor Jane Seymour, University of Nottingham, Nurses' decisions to use anticipatory prescriptions	34 healthcare professionals

Priority 3b

Patient assessment

We have monitored the impact on patient and carer satisfaction of the Marie Curie Managed Care Service model. This is a new way of supporting patients nearing the end of their lives to remain at home. The main components of the model are the assessment of patient needs by a Marie Curie Senior Nurse, the development of an individualised care plan for Marie Curie patients, and then the allocation of appropriate Marie Curie resource to provide care.

Patients in Belfast Health and Social Care Trust who received the service were asked for their feedback via a telephone survey. It captured feedback from 22 patients and carers who were being supported at that time and sought to gauge the level of satisfaction and experience of the service offered by the Marie Curie Nursing Service in the area.

Outcomes we achieved

- Positive indicators that the service is being well received by patients and their carers.

- Dissemination of lessons learnt in Northern Ireland across the charity UK wide.

Monitoring patients and carer satisfaction on the impact of the Marie Curie Managed Care service in Belfast.	**%**
Patients were satisfied with the service	100
Respondents felt that overall, the service met their needs well	91
Respondents felt that their needs around symptom control were well met	94
Respondents felt that their needs around having their questions answered were well met	89
Respondents found it easy to obtain the service	86
Patients believed that the service responded quickly to meet their needs	90
Respondents stated that the service was accessible all of the time it was needed	66*
Respondents felt that the service always effectively coordinated with other services	86
Respondents felt that the staff had a very good knowledge and understanding of their needs	91
Respondents had very high levels of confidence that the service provided good care	91
Respondents felt that having the service meant that they could remain at home.	91

*NB: The evaluation highlighted that 66% of patients and carers felt that the service was accessible at all times. Some respondents stated that they were unable to access the service out of hours, at the weekend and on a bank holiday. Unfortunately managed care was not set up with an out of hours remit, thus identifying a gap.

Priority 3c

Symptom management – breathlessness

Breathlessness is one of the most common and most difficult symptoms to manage in many advanced diseases and can be extremely distressing for both patients and their carers. It has a number of facets which include physical, psychological, spiritual and social components.

The first national audit of breathlessness was undertaken in 2011. The standards included in the audit were based around the work originally carried out by Corner et al (1996) who developed an approach to the management of breathlessness in lung cancer, based on rehabilitation techniques used in chronic pulmonary disease. Their work is based on the premise that the emotional and physical experience of breathlessness is inextricably linked and therefore requires more than mere pharmacological interventions.

The intervention is based on a 'meaning centred' approach in which therapeutic strategies are selected, based on the individual's interpretations of their illness and symptoms (Institute of Cancer Research, 2007). The aim is to improve quality of life and functional ability in the context of a life-threatening/limiting illness. The intervention has several elements which can be used when working with the different aspects of the patient's breathlessness experience:

- Clinical assessment

- Psychotherapeutic strategies – exploring the meaning of the illness/symptom

- Cognitive strategies: relaxation/distraction, anxiety management

- Behavioural/coping strategies: including breathing techniques and pacing

In 2012 a decision was made not to audit breathlessness symptom management as a new assessment package was being developed at the time. An audit will be carried out in 2013 to review best practice through use of this assessment package.

Priority 3d

Symptom management – pain

These are the results of the third Marie Curie national audit of pain assessment in hospices. The 2012 audit concentrated on day services and community patients only, following excellent audit results for in-patient services the previous year.

The following standards were applied for day services:

Day services	2010	2011	2012
Standard 1: A detailed initial formal pain assessment will be carried out for every patient on their first visit to day services.	57%	48%	65%
Standard 2: Patients will have an ongoing assessment of their pain in accordance with the needs of the individual patient (at each attendance at day services if not controlled*). *Controlled being three consecutive attendances with mild or no pain (score less than three).	80%	86%	95%
Standard 3: Each member of the clinical team with responsibility for symptom control and pain monitoring understands their role and responsibilities.	82%	90%	92%

The following standards were applied to community services:

Community	2010	2011	2012
Standard 1: A detailed initial formal pain assessment will be carried out for every patient on their first visit to day services.	76%	79%	91%
Standard 2: Patients will have an ongoing assessment of their pain in accordance with the needs of the individual patient (at each attendance at day services if not controlled*). *Controlled being three consecutive attendances with mild or no pain (score less than three).	73%	75%	92%
Standard 3: Each member of the clinical team with responsibility for symptom control and pain monitoring understands their role and responsibilities.	91%	100%	100%

NB: In-patient data was not collected for 2012. The previous year's data was of such a consistently high standard that a decision was taken by the Clinical Audit Group for this section to be excluded in 2012.

Priority 3e

Choosing where to die

Our aim:

All patients under the care of Marie Curie should have the option to discuss their preferred place of death if they wish to do so.

Definition:

Preferred Place of Death (PPD) should be taken as the most recent or last expressed wish made by the patient and recorded in the clinical records. If the patient is unable to express their wish then the family's view of where the patient would have wished to die should be recorded.

Outcomes we achieved

In 2012 the data collected for Preferred Place of Death was slightly inconsistent across hospices and therefore not adequate for the purposes of this report. In 2013/14 we will ensure that data is collected consistently as identified in our priorities.

Formal responses from stakeholder organisations

Statements from Marie Curie Cancer Care Expert Voice; Local Involvement Networks (Healthwatch); Overview and Scrutiny Committees (OSC) and Clinical Commissioning Groups (CCG).

Marie Curie Cancer Care Expert Voices representation

It is with a sense of pride that I approach this opportunity of commenting, publicly, on Marie Curie's Quality Account Report. As a one-time carer, retired businessman, with no medical qualifications, my input comes both from my heart as well as my head.

My wife of 47 years, Gillian, was diagnosed with Acute Myeloid Leukaemia on 13 September 2010. She died 26 days later. Following a period in an NHS hospital she had been released into home palliative care some 10 days before her death. Marie Curie were part of that journey for only the last critical 14 hours, but the experience was so profound that I volunteered my services shortly afterwards.

I give huge credit to the charity in that from the outset they proactively tapped into my past business acumen, involving me in several projects specifically focussing on patient and carer enhancements and demonstrably valuing my previous personal and career expertise.

Last year when I viewed the previous report my first impression was that it was too 'wordy'. The cynic in me whispered that the focus was too compliance focussed. How wrong that has proved to be. In accepting that compliance is an important 'safety net' for all of us I have since been convinced, through experience and exposure, that the charity continually strives to enhance patient and carer experience, and that this is focal to every decision made. Every dimension of the Quality Account Report has this 'patient and carer first' visionary objective interwoven as a 'red thread' throughout.

Over the last two years my voluntary work has seen me on project boards, chairing survey outcome work streams, as an integral member of their 'Expert Voices' feedback team and, quite recently, as part of a Compliance Team, visiting hospices in the north of England. At all and every stage of such involvements I have been impressed by the dedication of all involved.

My opportunity, now, to comment on this important piece of work would seem to be a natural progression on my involvement to date. As an ex-carer who has been gratefully on the receiving end of end-of-life palliative care, I am proud to endorse that the content and relevance of the Quality Account Report, matches the enthusiasm and genuine caring attitude of all involved within Marie Curie Cancer Care.

Brian Andrews
Expert Voice member

Lincolnshire West Clinical Commissioning Group (CCG)

Thank you for the opportunity to comment on the 2012/13 Quality Account Report for Marie Curie Cancer Care. It is an informative and easy to understand report. Lincolnshire West CCG commends the work evidenced to improve the quality of care provided to patients, their carers and families for the three domains of patient experience, patient safety and clinical effectiveness.

Areas the CCG is particularly pleased to note in the domain of patient experience for 2012/13 are the establishment of the Expert Voices Group; the work to make focused improvements on four areas identified by patients/carers for each hospice; the positive outcomes from the in-patient survey; and the valuable work of the Rapid Response Service in Lincolnshire as just one of the examples of how the organisation is ensuring accessibility and the provision of better care.

The CCG endorses the further work proposed to improve patient experiences by expanding avenues to listen, action and feedback on the patient/carer 'voice'. The CCG also welcomes the initiatives concerning end-of-life care with regard to dementia, care homes and the work programme with the Royal College of General Practitioners to help General Practitioners improve the care they provide to terminally ill people.

For the quality domain of patient safety the CCG recognises the work undertaken in 2012/13 relating to medicines management, infection control and assuring patient notes are in the home for continuity of care. The initiative to establish a safety thermometer measuring and improving five relevant key safety issues in 2013/14 is acknowledged and will ensure focus is maintained on medicines management and infection control, but will add additional key areas of action including falls, pressure ulcers and record keeping.

The Quality Account very clearly outlines the extent to which the organisation is dedicated to improving clinical effectiveness and care by reliably undertaking and contributing to research into palliative and end-of-life care. The CCG commends the commitment to research and the dissemination of learning from the research through the Research into Practice Group and annual conference.

In summary the CCG is pleased to endorse the Quality Account as a clear and accurate description of quality improvement work programmes undertaken in 2012/2013 and those planned for 2013/14. The CCG thanks Marie Curie staff and volunteers for their dedication, achievements and quality improvement aspirations as outlined within the Account.

Wendy Martin
Executive Lead Nurse & Midwife
Lincolnshire West CCG

Comments from Health and Adult Services Scrutiny Committee, London Borough of Lambeth

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).

The committee believes that there should be some form of national oversight of the QAs of national organisations. However 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 does the committee 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 the 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 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

Healthwatch – Southwark

Unfortunately we will not be able to comment on the Marie Curie Accounts as we are in the process of commenting on our three Acute Providers.

Sec-Chan Hoong
Healthwatch Southwark Development Manager
sec-chan@healthwatchsouthwark.co.uk

Statement of Directors' Responsibilities in respect of the Quality Account

The Directors are required under the Health Act 2009 to prepare a Quality Account for each financial year. The Department of Health has issued guidance on the form and content of annual Quality Accounts (which incorporates the legal requirements in the Health Act 2009 and the National Health Service (Quality Reports) Regulations 2010 (as amended by the National Health Service (Quality Accounts) Amendments Regulations 2011).

In preparing the Quality Account, directors are required to take steps to satisfy themselves that:

- The Quality Account presents a balanced picture of the charity's performance over the period covered
- The performance information reported in the Quality Account is reliable and accurate
- There are proper internal controls over the collection and reporting of the measures of performance included in the Quality Account, and these controls are subject to review to confirm that they are working effectively in practice
- The data underpinning the measures of performance reported in the Quality Account is robust and reliable, conforms to specified data quality standards and prescribed definitions, and is subject to appropriate scrutiny and review; and
- The Quality Account has been prepared in accordance with Department of Health guidance

The directors confirm to the best of their knowledge and belief they have complied with the above requirements in preparing the Quality Account.

By order of the Board

John Varley
Chairman
1 June 2013

Jane Collins
Chief Executive
1 June 2013

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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London
SE1 7TP

Email: Qualityassurance@mariecurie.org.uk

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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.

mariecurie.org.uk

Marie Curie
Cancer Care