

# **Palliative Care Pathway Board**

## Annual Report 2013/14

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Pathway Manager: Hodan Noor

## Executive summary

1. Palliative care improves the quality of life of individuals and their families facing the problems associated with life-threatening illness. This involves the prevention and relief of suffering by early identification, assessment and treatment of pain and other symptoms, and the provision of psychosocial and spiritual support (WHO 2003).
2. Historically palliative care was used as the only option for a patient when **active treatment had failed**. Today, **in the twenty-first century, palliative care is gaining expertise** and is much wider than the provision of symptom relief to the dying; palliative care **includes care and support of the living**. The case for early palliative care for patients with cancer is advocated in a number of studies which demonstrate improved patient and carer outcomes and reduced costs (Zimmermann et al 2014, Temel et al 2011).
3. Recent reports have highlighted variability in palliative and end of life care provision across the UK. The **Independent Review of the Liverpool Care Pathway** (Neuberger et al 2013) and the **National Care of the Dying Acute Hospitals** (RCP 2014) demonstrate that the **NICE guidance on Supportive and Palliative Care published in 2004 is yet to be fully implemented**. Furthermore, around half the deaths in England occur in hospitals (ONS 2012) despite most people with cancer stating, they would rather die at home or in a hospice.
4. National recommendations are available for the minimum requirements of **specialist palliative care provision** (APM et al 2012). The Association of Palliative Medicine is currently reviewing the consultant workforce; this will include the estimated workforce required over the next five years to meet changing demands.
5. The Greater Manchester and Cheshire Cancer Network Palliative and End of Life Care Cross-cutting Group (CCG) was established in 2007. Following **the reconfiguration** of networks nationally in 2013, this cross-cutting group continued to operate, under the **Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network (SCN)**. In early 2014, this CCG group dissolved and a Palliative and End of Life Care Network Advisory Group (NAG) for adults across Greater Manchester functioning on behalf of the SCN was established. The purpose of this group is to **support the implementation of national/regional policy** on palliative and end of life care for all adults irrespective of their disease; this includes non-cancer diagnoses.

## Challenges

6. All of the NHS acute Trusts in Manchester Cancer participated in the **National Care of the Dying Audit for Hospitals (RCP 2014)**. This audit involved a retrospective case note review of a sample of all patients who died in hospital during May 2013. The standards of care were based on relevant national policy (DH 2008; DH 2009; DH 2010; DH 2012a; DN 2012b, DH 2013, CQC 2010, NICE 2011, GMC 2010) and the questions were informed by the 44 recommendations of the Independent Review of the Liverpool Care Pathway (Neuberger et al 2013).

6.1. Key organisational elements that underpin the delivery of care including relevant structures, processes and policies were audited. The national key findings included:

- Only 21% of sites had access to **face-to-face palliative care services 7 days per week**, despite a longstanding national recommendation that this be provided; most (73%) provided face-to-face services on weekdays only. **Locally only 2 out of the 12 Trusts achieved KPI 2.**
- **Mandatory training in care of the dying** was only required for doctors in 19% of trusts and for nurses in 28%, despite national recommendations that this be provided. 82% of trusts had provided some form of training in care of the dying in the previous year; 18% had not provided any. **Locally only 2 out of the 12 Trusts achieved KPI 3;** this measured the provision of continuing education, training and audit.

Name of the site participating in the audit	Bolton NHS Foundation Trust	Central Manchester University Hospitals NHS Foundation Trust	Christie NHS Foundation Trust	East Cheshire NHS Trust	Fairfield General Hospital	North Manchester General Hospital	Royal Albert Edward Infirmary	Royal Oldham Hospital	Salford Royal NHS Foundation Trust	Stepping Hill Hospital	Tameside Hospital NHS Foundation Trust	University Hospital of South Manchester NHS Foundation Trust
<i>KPI 1: Access to information relating to death and dying. (range 0-5 5=achieved)</i>	5	5	5	4	5	5	4	5	5	4	4	4
<i>KPI 2: Access to specialist support for care in the last hours or days of life. (Range 0-5 4-5= achieved)</i>	4	2	2	2	2	2	2	2	3	2	4	2
<i>KPI 3: Care of the Dying: continuing education, training and audit. (range 0-20 10or higher =achieved)</i>	8	8	11	12	5	5	0	5	8	7	5	4
<i>KPI 4: Trust Board representation and planning for care of the dying. (range 0-4 4=achieved)</i>	1	4	4	1	1	1	4	1	3	4	1	1
<i>KPI 5: Clinical protocols for the prescription of medications for the 5 key symptoms at the end of life. (Range 0-5 5=achieved)</i>	5	5	5	5	5	5	5	5	5	5	5	5
<i>KPI 6: Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient. (range 0-9 9=achieved)</i>	9	9	9	9	9	9	7	9	9	6	7	4
<i>KPI 7: Formal feedback processes regarding bereaved relatives/friends views of care delivery. (Range 0-4 1or higher achieved)</i>	1	0	0	3	3	3	0	3	0	0	0	

7. Palliative care expands across the whole cancer pathway and across all the disease groups; the demand for palliative care will rise due to the increase in cancer prevalence; the need for proactive integration of palliative care for patients receiving systemic anti-cancer therapies; the rapidly ageing population; increasing multiple co-morbidities.

8. Specialist palliative care services are under resourced to enable the provision of a 7 day face to face specialist palliative care service and 24/7 access to specialist palliative care advice.

9. Influencing the development of integrated clinical data systems to include palliative and end of life care. The implementation of the electronic palliative care coordination system (EPaCCS) is at variable stages across Manchester Cancer. Established EPaCCS are beginning to show improvements in quality of care with the potential to generate efficiency savings through reductions in unwanted and inappropriate interventions and emergency admissions to hospital.
10. Establishing an effective infrastructure for palliative and end of life care research and education including dedicated experts within the current financial envelop.

## *The vision and objectives*

11. Every person affected by cancer and their relatives/carers in Manchester Cancer will have their needs assessed, their wishes and preferences discussed where appropriate, and an agreed set of actions reflecting the choices they make about their care. This will include those people, receiving anti-cancer treatments, living with cancer and those in the advanced stages of the disease. Every person will be offered a range of physical, emotional, spiritual and social support to improve their quality of life.
12. The Board will promote the implementation of the Electronic Palliative Care Co-ordination System (EPaCCS) for End of Life Care (EoLC) to improve the recording, communication and coordination of care thereby providing better quality care for patients.
13. To map the integration of palliative care (generalist and specialist) service provision into oncology care in collaboration with the SCN and the Living With and Beyond pathway board. The findings will provide options on the way forward in achieving national standards.

## 1. Introduction

2013/14 was a transitional year for cancer services in Greater Manchester and East Cheshire. The Greater Manchester and Cheshire Cancer Network ceased to exist in March 2013 when cancer networks nationally were amalgamated into strategic clinical networks as part of the NHS reorganisation. In Greater Manchester this coincided with the creation of Manchester Cancer, an integrated cancer system for Greater Manchester and East Cheshire.

Twenty Manchester Cancer Pathway Clinical Directors were appointed in late 2013 and took up their roles on 1<sup>st</sup> January 2014. They spent the first months in post forming their Pathway Boards, multi-professional clinical groups from across the region. These pathway Boards are now formed and most had their first meeting in April/May of 2014.

As such, this is a transitional annual report. It outlines the current configuration of services, the progress in forming the Pathway Board, the data on outcomes and experience that the Board took into account when setting its objectives, and what those objectives are for 2014/15 and beyond. In July 2015 every Manchester Cancer Pathway Board will publish a full annual report, outlining the work of its first full year and its progress against those objectives.

This annual report is designed to:

- Provide a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard it is the key document for the Board.
- Provide an overview to the hospital trust CEOs and other interested parties about the current situation across Manchester Cancer in this particular cancer area
- Meet the requirements of the National Cancer Peer Review Programme
- Be openly published on the external facing website.

## 2. General overview

Palliative care improves the quality of life of individuals and their families facing the problems associated with life-threatening illness. This involves the prevention and relief of suffering by early identification, assessment and treatment of pain and other symptoms, and the provision of psychosocial and spiritual support.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Support patients to live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their bereavement (WHO 2003).

However, the terminology that has developed around this area of care is poorly understood and lacks clarity. Such terms, including palliative care, hospice care, supportive care, specialist palliative care, generic or general(ist) palliative care, end of life care, are not always used clearly or consistently (see Glossary for full definitions).

Thus, many people remain fearful of palliative care as it is often *wrongly* considered as being synonymous with terminal care and is therefore associated with imminent death and 'hopelessness'. Historically palliative care was used as the only option for a patient when active treatment had failed. Today, in the twenty-first century, palliative care is gaining expertise and is much wider than the provision of symptom relief to the dying; palliative care includes care and support of the living. The case for early palliative care for patients with cancer is advocated in a number of studies which demonstrate improved patient and carer outcomes and reduced costs (Zimmermann et al 2014, Temel et al 2011). A study comparing early diagnosed metastatic non-small cell lung cancer patients to receive either early palliative care integrated with standard oncology care or standard oncology care alone, showed that the intervention group not only had better quality of life and reduced symptom burden but also less aggressive care towards the end of life and longer survival (Temel et al 2010). Furthermore, a systematic review on cost and non-clinical outcomes indicates that specialist palliative care is associated with fewer hospitalisations, fewer intensive care hospital days and lower overall costs (Smith and Cassel 2009).

National guidance to improve palliative and end of life care has come from a number of sources over the last decade, including NICE Improving Supportive and Palliative Care for Adults with Cancer (2004), End of Life Care Strategy (DH 2008), NHS Healthier Horizons for the Northwest (2008), National Confidential Enquiry into Patient Outcome and Death (2008, 2009), Quality Markers for End of Life Care (2009), NICE End of Life Care Quality Standard (DH 2011), Peer Review for Specialist Palliative Care (2012), Electronic Care Co-ordination System (EPaCCS) (Public Health England 2013), National Care of the Dying Acute Hospitals (RCP 2014), One Chance to Get it Right (LACDP 2014).

### **The key recommendations include:**

- Proactive integration of palliative and end of life care for patients receiving systemic anti-cancer therapies (SACT) especially where treatment is palliative.
- Oncology teams to facilitate discussions with patients around treatment and/or management choices; patients are unlikely to enter into discussions about advance directives, preferred place of death and the involvement of palliative care services unless they know that these are options and that they have the right to express their preferences.
- Patients with palliative care needs are identified using recognised criteria and management plans initiated in discussion with the multidisciplinary team.
- Regular assessment of patients and carers using validated assessment tools.
- Patient and carer needs are communicated within the team and to specialist colleagues, where appropriate.
- Preferred priorities for care (DH 2011) and place of death are openly discussed and noted and measures made to facilitate an individual's preferences where possible.
- There should be a named person within the care team to co-ordinate care.
- Relevant information should be available to out-of-hours providers and carers.

- Care in the dying phase should meet the new five care priorities (Leadership Alliance for the Care of Dying People 2014).
- Carers should be involved, educated and supported to care for the patient in the ways they choose. Information is critical - whether medical, financial or bereavement support.
- Audit and research
- There should be a trained workforce to provide palliative care services.
- Mandatory education and training for all staff caring for patients in the last days of life.
- 24/7 district nursing service.
- Timely and appropriate referrals to specialist palliative care services for those patients with complex needs.
- Provision of a face-to-face specialist palliative care service from at least 9am to 5pm, 7 days per week and 24/7 access to specialist palliative care advice.

Furthermore, end of life care was one of 12 national work streams of the Quality, Innovation, Productivity and Prevention (QIPP) programme. The QIPP indicators for end of life care are:

1. Improve scores on the Death in the Usual Place of Residence indicator.
2. Reduce the number of hospital admissions of 8 days or more, which end in death.
3. Reduce emergency admissions in the last year of life.

This work stream therefore aimed to increase the number of people identified who are approaching the end of lives in order to support them to live and die well in their preferred place. The development of an Electronic Palliative Care Co-ordination Systems (EPaCCS) was identified as a mechanism for enabling co-ordination and supporting communication between the professionals and services delivering care. In March 2012, a national information standard for End of Life Care Co-ordination (ISB 1580) was published with an implementation date of 1 December 2013. Responsibility for the national information standard now sits with the Standardisation Committee for Care Information (SCCI); the Information Standards Board closed on 31 March 2014. Elements of this work stream continue as part of the new NHS system.

There are two distinct groups of health and social care professionals involved in providing palliative care:

- 'Non-specialists' involved in day-to-day care and support of patients and their carers in their homes and hospitals. This group should be able to assess and meet the patient care needs under ordinary circumstances or to seek advice from/refer to specialist palliative care services in more challenging situations. Thus multidisciplinary teams who provide services for patients with cancer fall into this category.
- Specialist palliative care services are provided by specialist multidisciplinary palliative care teams (e.g. consultants in palliative care, nurse specialists, AHPs). Delivery of care may be via hospital and/or community teams, hospice, day centres and telephone advice services. They also provide education and training in palliative care. Specialist palliative care funding is in part from statutory (NHS) and from voluntary organisations, charities and local-fundraising. Only 34%, on average, of adult hospice income comes from the NHS.

Commissioning specialist palliative care can help commissioners achieve a number of wider commissioning goals, especially in relation to Domain 2, *enhancing quality of life for people with long-term conditions* and Domain 4, *ensuring that people have a positive experience of care*, of the NHS Outcomes Framework (DH 2012a) and in delivering the above QIPP indicators for end of life care.

National recommendations are available for the minimum requirements of specialist palliative care provision (APM 2012). The Association of Palliative Medicine is currently reviewing the consultant workforce; this will include the estimated workforce required over the next five years to meet changing demands. It is important to note these recommendations do not take into account local variations nor do they reflect the impact of changing expectations.

Per population of 250,000, the MINIMUM requirements are:

- Consultants in palliative medicine – 2 whole time equivalent (WTE)
- Additional supporting doctors (e.g. trainee/specialty doctor) – 2 WTE
- Community specialist palliative care nurses – 5 WTE
- Inpatient specialist palliative care beds: 20-25 beds with 1.2 nurse : bed ratio

Per 250-bed hospital, the MINIMUM requirements are:

- Consultant/associate specialist in palliative medicine – 1 WTE
- Hospital specialist palliative care nurse – 1 WTE

The following caveats apply to the above MINIMUM recommendations:

- Tertiary cancer centres will require more than the above minimum requirements
- Each specialist palliative care team will require input from a multi-professional team including occupational therapists, physiotherapists, social workers, chaplaincy and administration, as a minimum.
- These figures do not take into account the education and training responsibilities and 7 day working.
- The rapidly ageing population and increasing multiple comorbidities requires more specialist palliative care provision.
- Local considerations (rural/urban, ethnicity, deprivation, mixed funding streams, etc.) need to strongly inform what SPC is commissioned.

Recent reports have highlighted variability in palliative and end of life care provision across the UK. The recent Independent Review of the Liverpool Care Pathway (Neuberger et al 2013) and the National Care of the Dying Acute Hospitals (RCP 2014) demonstrate that the NICE guidance published in 2004 is yet to be fully implemented.

Furthermore, around half the deaths in England occur in hospitals (ONS 2012) despite most people with cancer stating, they would rather die at home or in a hospice.

For this reason, trust boards, managers and clinicians should recognise that a core responsibility of organisations and clinicians is to deliver high-quality palliative and end of life care for patients and appropriate support to their families, carers and those close to them.

## 3. Background to the pathway/cross-cutting area

The Greater Manchester and Cheshire Cancer Network Palliative and End of Life Care Cross-cutting Group (CCG) was established in 2007. Following the reconfiguration of networks nationally in 2013, this cross-cutting group continued to operate, under the Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network (SCN). In early 2014, this CCG group dissolved and a Palliative and End of Life Care Network Advisory Group (NAG) for adults across Greater Manchester functioning on behalf of the SCN was established. The purpose of this group is to support the implementation of national/regional policy on palliative and end of life care for all adults irrespective of their disease; this includes non-cancer diagnoses.

Concurrently, the Manchester Cancer Palliative Care Board was formed to promote, enhance, improve and extend the provision of palliative care services to patients with cancer and their families across Greater Manchester. The Board is able to offer to policy makers, planners, service managers and practitioners valuable opportunities for the development, sharing and implementation of expert opinion, sound strategy and good practice.

The Network Advisory Group and the Palliative Care Board endorse the need to work cohesively to yet be accountable to the Strategic Clinical Network and Manchester Cancer respectively.

## 4. Configuration of services

Palliative Care service provision across Greater Manchester is not exclusive to cancer care. The provision of generic and specialist palliative support for patients is addressed with the Strategic Clinical Network configuration described in the table below;

<b>NHS Hospital Specialist Palliative Care Service (SPC)</b>	<b>Community Specialist Palliative Care Services</b>	<b>Hospices</b>
Pennine Acute Hospital Trust The Royal Oldham	Pennine Care NHS Foundation Trust – Oldham Community Specialist Palliative Care Service	Dr Kershaw’s <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul>
Fairfield Hospital	Pennine Care NHS Foundation Trust – Bury Community Specialist Palliative Care Service	Bury * <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Hospice at Home</li> <li>• Outpatients</li> </ul>
North Manchester General Hospital	Pennine Acute Hospital NHS Trust – North Manchester Community Specialist Palliative Care Service	Springhill <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients (ad hoc)</li> </ul>

Rochdale Infirmary covered by Fairfield Hospital	Pennine Care NHS Foundation Trust – Heywood, Middleton and Rochdale Community Specialist Palliative Care Service	Springhill * <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Hospice at Home</li> <li>• Outpatients (ad hoc)</li> </ul>
Royal Bolton NHS Foundation Trust	Royal Bolton NHS Foundation Trust – Bolton Community Specialist Palliative Care Service	Bolton * <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Hospice at Home</li> <li>• Outpatients</li> </ul>
Central Manchester University Hospitals NHS Foundation Trust	Central Manchester & Manchester Children’s University Hospitals Foundation Trust – Central Manchester Community Specialist Palliative Care Service	St Ann’s Heald Green <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul> St Ann’s Little Hulton <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul>
<b>NHS Hospital Specialist Palliative Care Service (SPC)</b>	<b>Community Specialist Palliative Care Services</b>	<b>Hospices</b>
University Hospital of South Manchester NHS Foundation Trust	South Manchester University Hospitals NHS Trust – South Manchester Community Specialist Palliative Care Service	St Ann’s Heald Green <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul> Neil Cliffe Centre +
Central Manchester University Hospitals NHS Foundation Trust (Trafford Division)	Central Manchester University Hospitals NHS Foundation Trust – Trafford Community Specialist Palliative Care Service	St Ann’s Heald Green * <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Hospice at Home</li> <li>• Outpatients</li> </ul>
Wrightington, Wigan & Leigh NHS Foundation Trust	Wigan and Leigh Hospice Community Specialist Palliative Care Service	Wigan & Leigh Hospice <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul>
Stockport NHS Foundation Trust	Stockport NHS Foundation Trust – Stockport Community Specialist Palliative Care Service	St Ann’s Heald Green <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul>
Tameside Hospitals NHS Foundation Trust	Stockport NHS Foundation Trust – Tameside & Glossop Community Specialist Palliative Care Service	Willow Wood <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> </ul>

		<ul style="list-style-type: none"> <li>• Outpatients</li> </ul>
East Cheshire NHS Foundation Trust Integrated Specialist Palliative Care Services.	East Cheshire NHS Foundation Trust Integrated Specialist Palliative Care Services.	East Cheshire <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> </ul>
Salford Royal NHS Foundation Trust	St Ann’s Salford Community Specialist Palliative Care Team	St Ann’s Hospice <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Hospice at Home</li> <li>• Outpatients</li> </ul>
Mid Cheshire Hospitals NHS Foundation Trust	Mid Cheshire NHS Foundation Trust – Mid Cheshire Community Specialist Palliative Care Service	St Luke’s Winsford <ul style="list-style-type: none"> <li>• In Patient Services</li> <li>• Day Therapy</li> <li>• Outpatients</li> </ul>
The Christie NHS Foundation Trust	Liaises with all Service providers	Liaises with all service providers

The Christie is the lead Oncology Centre with two satellite centres providing treatments in Salford and Oldham. Over 80% of the Manchester Cancer population is from Greater Manchester and less than 20% from Central and Eastern parts of Cheshire.

\*All Hospices include day therapy facilities in Greater Manchester.

+Neil Cliffe Centre is part of St Ann’s Hospice and provides out-patient services to people at any stage of their illness. Support services are also available to patients, families and carers.

Hospice at Home Services are provided by Bolton Hospice; St Ann’s Hospice for Salford and Trafford; Springhill Hospice; Bury Hospice – these services are not solely specialist palliative care; they also provide general palliative care services and invaluable support to patients, families and carers.

## 5. Clinical guidelines

Clinical guidelines in palliative and end of life care have been developed by the previous network cross-cutting group. These, together with relevant peer review documentation have been uploaded on the new SCN website [www.gmccn.nhs.uk](http://www.gmccn.nhs.uk) (quick link to documents <http://www.gmlscscn.nhs.uk/end-of-life/eol-docs.php>). The SCN actively supports Manchester Cancer in adopting these guidelines and thus will be duplicated on the Manchester Cancer website over the coming months [www.manchestercancer.org](http://www.manchestercancer.org).

A full list of active current guidelines and their renewal dates will be produced for the updated constitution of July 2015. These will be developed in collaboration with the SCN to promote consistency and high quality evidence based clinical care in palliative and end of life care. This will also ensure the best use of finite resources.

## 6. Clinical information and outcomes

### 6.1 Specialist Palliative Care MDT Peer Review

The current peer review measures for specialist palliative care MDTs are to be revised with a publication date of 2015. Meanwhile, organisations are encouraged to upload self-assessments on the CQUINs website with internal validation. Thus data is available on the CQUINs website for 2013.

### 6.2 Care Quality Commission

Following the recent national concern around care of the dying and the subsequent publications of *National Care of the Dying Acute Hospitals Audit* (RCP 2014) and *One Chance to Get it Right* (NLACDP 2014), the Care Quality Commission (CQC) have included end of life care as one of the eight core services to be inspected in acute hospitals and across other appropriate settings. These reports will become available as the inspections progress during 2013/14.

### 6.3 National Care of the Dying Audit for Hospitals, Round 4, England

All of the NHS acute Trusts in Manchester Cancer participated in the National Care of the Dying Audit for Hospitals (RCP 2014).

This audit involved a retrospective case note review of a sample of all patients who died in hospital during May 2013. The standards of care were based on relevant national policy (DH 2008; DH 2009; DH 2010; DH 2012a; DN 2012b, DH 2013, CQC 2010, NICE 2011, GMC 2010) and the questions were informed by the 44 recommendations of the Independent Review of the Liverpool Care Pathway (Neuberger et al 2013).

This audit comprised the following three sections:

- **An organisational audit** – key organisational elements that underpin the delivery of care including relevant structures, processes and policies.
- **A case note review** – a consecutive, anonymised case note review of the all patients who died (excluding sudden unexpected deaths) within participating sites within a defined timeframe. Clinical data were recorded from consecutive case-notes of at least 50 patients per site.
- **An optional local survey** of the views of bereaved relatives or friends – using a validated self-completion questionnaire (CODE) (Mayland et al 2014) to assess care delivery in the last days of life. Those that wished to participate sent out anonymised questionnaires to relevant families or friends which could either be completed online or in hard copy.

All the data were analysed descriptively and key performance indicators for the organisational and clinical elements were developed, reflecting accepted national standards.

Each participating site across Manchester Cancer received an individual report of their performance against the national sample for the organisational and case note review elements of the audit. The results of the national sample for the local survey of bereaved relatives' views were also included.

## 6.3.1 Key findings

### National Organisational key findings

- Only 21% of sites had access to face-to-face palliative care services 7 days per week, despite a longstanding national recommendation that this be provided; most (73%) provided face-to-face services on weekdays only.
- Mandatory training in care of the dying was only required for doctors in 19% of trusts and for nurses in 28%, despite national recommendations that this be provided. 82% of trusts had provided some form of training in care of the dying in the previous year; 18% had not provided any.
- 53% of trusts had a named board member with responsibility for care of the dying; 47% did not. In 42% of trusts care of the dying had not been discussed formally at trust board in the previous year and only 56% of trusts had conducted a formal audit of such care, despite previous recommendations that this be carried out at least annually.
- Only 47% of trusts reported having a formal structured process in place to capture the views of bereaved relatives or friends prior to this audit.

Below are the Greater Manchester organisational KPI results;

Name of the site participating in the audit	Bolton NHS Foundation Trust	Central Manchester University Hospitals NHS Foundation Trust	Christie NHS Foundation Trust	East Cheshire NHS Trust	Fairfield General Hospital	North Manchester General Hospital	Royal Albert Edward Infirmary	Royal Oldham Hospital	Salford Royal NHS Foundation Trust	Stepping Hill Hospital	Tameside Hospital NHS Foundation Trust	University Hospital of South Manchester NHS Foundation Trust	Royal Oldham Hospital
KPI 1: Access to information relating to death and dying. (range 0-5 5=achieved)	5	5	5	4	5	5	4	5	5	4	4	4	5
KPI 2: Access to specialist support for care in the last hours or days of life.(Range 0-5 4-5= achieved)	4	2	2	2	2	2	2	2	3	2	4	2	2
KPI 3: Care of the Dying: continuing education, training and audit. (range 0-20 10or higher =achieved)	8	8	11	12	5	5	0	5	8	7	5	4	5
KPI 4: Trust Board representation and planning for care of the dying. (range 0-4 4=achieved)	1	4	4	1	1	1	4	1	3	4	1	1	1
KPI 5: Clinical protocols for the prescription of medications for the 5 key symptoms at the end of life. (Range 0-5 5=achieved)	5	5	5	5	5	5	5	5	5	5	5	5	5
KPI 6: Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient. (range 0-9 9=achieved)	9	9	9	9	9	9	7	9	9	6	7	4	9
KPI 7: Formal feedback processes regarding bereaved relatives/friends views of care delivery. (Range 0-4 1or higher achieved)	1	0	0	2	2	2	0	2	0	0	0	0	2

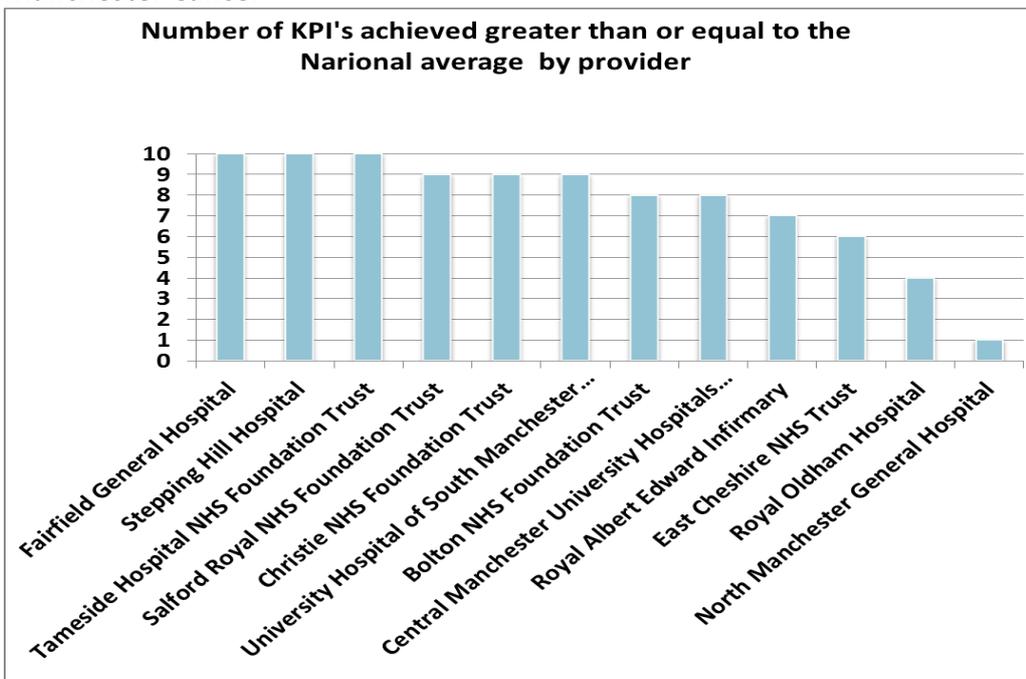
### National Case note review key findings

- Most patients (87%) had documented recognition that they were in the last hours or days of life, but discussion with patients was only documented in 46% of those thought capable of

participating in such discussions. Communication with families and friends was recorded in 93% of cases. These discussions occurred on average 31 hours prior to death.

- There was documentation of discussions about spiritual needs in only 21% of patients thought capable of participating in such discussions. In only 25% of cases was it documented that relatives/carers were asked about their own needs.
- In keeping with national guidance, most patients (63-81%) had medication prescribed 'as required' for the 5 key symptoms which may develop at the end of life. In the last 24 hours of life, 44% received medication for pain and 17% for dyspnoea. 28% had a continuous subcutaneous infusion of medication via a syringe driver.
- An assessment of the need for clinically assisted (artificial) hydration (CAH) was recorded for 59% of patients, but discussions with the patient were recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 36% of cases. CAH was in place in 29% of patients at the time of their death.
- An assessment of the need for clinically assisted (artificial) nutrition (CAN) was recorded for 45% of patients, but discussions with the patient recorded in only 17% of those thought capable of participating in such discussions. There was documented discussion with relatives and friends in 29% of cases. CAN was in place in 7% of patients at the time of their death.
- In keeping with national guidance, most patients (82%) were assessed five or more times in the final 24 hours of life.

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**Manchester Cancer**



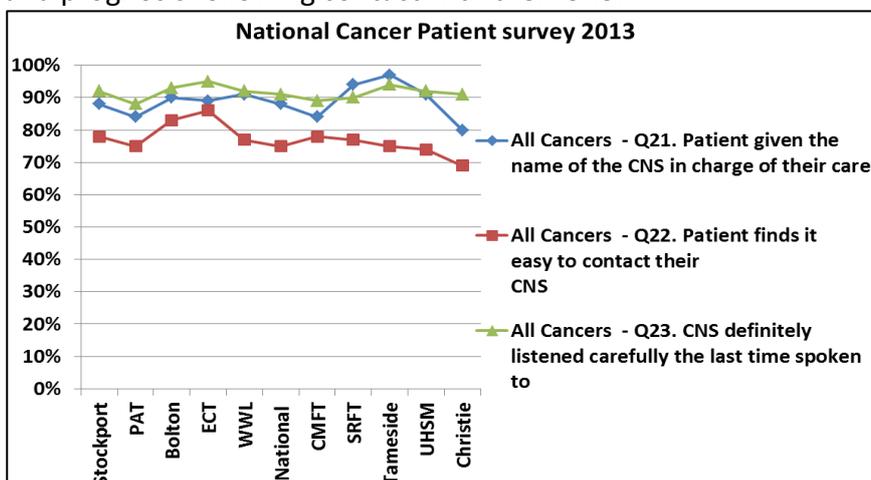
## 6.3.2 Key recommendations

- Hospitals should provide at a minimum face-to-face specialist palliative care service 9am to 5pm, 7 days per week.
- Education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training, and skills for supporting families and those close to dying patients.
- All hospitals should undertake local audit of care of the dying, including the assessment of the views of bereaved relatives, at least annually.
- All trusts should have a designated board member and a lay member with specific responsibility for care of the dying. Trust boards should formally receive and discuss the report of local audit at least annually.
- The decision that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient's care. This should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.
- Pain control and other symptoms in dying patients should be assessed at least 4- hourly and medication given promptly if necessary. Interventions should be discussed with the patient where possible and appropriate, and with family, carers or other advocate.
- Decisions about the use of CAN and CAH are complex and should be taken by a senior experienced clinician supported by a multidisciplinary team. They should be discussed with the patient where possible and appropriate, and with family, carers or other advocates.
- Hospitals should have an adequately staffed and accessible pastoral care team to ensure that the spiritual needs of dying patients and those close to them are met.

## 7. Patient experience

Palliative and end of life care did not feature in the National Cancer Patient Experience Survey. However, the impact of Clinical Nurse Specialists (CNS) by tumour groups was surveyed; these findings are applicable to CNSs working in Palliative Care.

The importance of patients having the name of a CNS is confirmed. Those patients with a CNS gave more positive answers than did those patients who did not have one. The findings indicated improved quality of care for cancer patients with improved understanding of treatment options and prognosis following contact with their CNS.



It is thus important to establish any significant variations in access to palliative care CNSs across Manchester Cancer.

## 8. Research and clinical trials

In comparison to oncological research, Specialist Palliative Care research is in its infancy, and has been slow to develop. This may have arisen in part due to ethical considerations around involving patients in clinical studies at the end of their lives, an element of 'gate-keeping' on the part of palliative care professionals and a lack of funding and research experience within the specialty. However, research in palliative care has increased considerably over recent years, both in terms of clinical and observational studies and the Palliative Care Board is keen to ensure that Manchester is an active centre of research in the specialty.

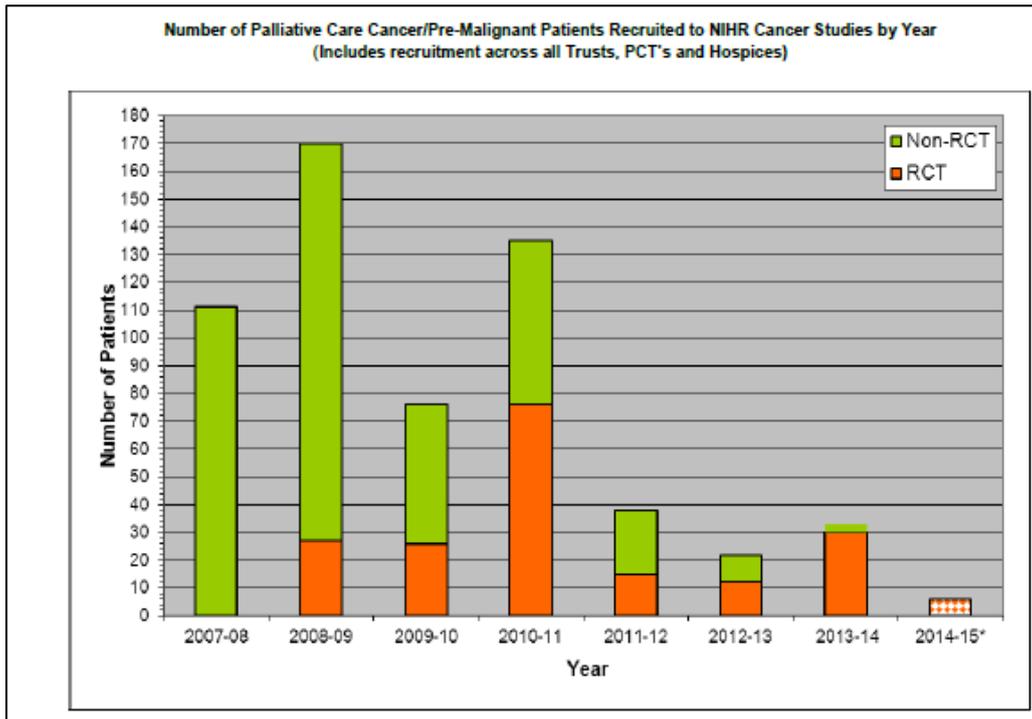
Research in relation to Specialist Palliative and End of Life Care in cancer will be undertaken in collaboration with the nominated Palliative Care Research Lead, Dr Iain Lawrie, for Manchester Cancer Palliative Care Board and the SCN Palliative Care and End of Life Care Advisory Group. The Palliative Care Board is keen to engage and collaborate with partners currently providing palliative care in primary, secondary, tertiary and independent sectors, as well as academic institutions (e.g. The University of Manchester) and organisations (e.g. Palliative Research in Manchester, Palliative Care Research Society) in order to ensure an effective, coordinated and meaningful approach to research into palliative and end of life care.

Priority studies for entry into clinical trials will be agreed with Manchester Cancer Palliative Care Board, although responsibility for involvement, conduct and administration of studies will remain with individual organisations. Wherever possible, studies should be nationally recognised in order to ensure professional research nurse support and national recognition of recruitment. However, this should not preclude organisations described above from conducting non-portfolio research relating to palliative and end of life care.

The recent report around the care of dying people and their families *One chance to get it right* (2014) highlights the need for greater understanding of how people who are dying, and their relatives and carers, experience care at the end of life; and greater understanding of the social and health effects of different experiences of dying on individuals and on their families.

Furthermore, the National Institute for Health Research (NIHR) has commissioned updates of Cochrane reviews of evidence on medically assisted nutrition and hydration for palliative care patients (Cochrane Collaboration, April 2014) and has also commissioned a mapping of evidence requirements flowing from the Priorities for Care initiative. The results of this mapping exercise will inform the programme of future research around the care of people in the last few days and hours of life.

The most recent research activity baseline (from the predecessor group to the SCN Palliative Care and End of Life Care Advisory Group) dates from 2013/2014 and shows an increase from the previous year 2012/13. Below is a breakdown of recruitment performance by Trusts during this period.



**Recruitment Performance by Trust in 2013-14\***

	RCT/ non RCT	Bolton	Central	Christie	East Cheshire	Mid Cheshire	Pennine	Salford	UHSM	Stockport	Tameside	Wigan	Total
			MRI						Wyth				
HOT (previously NEON)	RCT	-	-	-	-	-	4	-	-	-	-	-	4
IMPACT Programme Grant	non RCT	-	-	-	-	-	-	-	-	-	-	-	0
NCRN154	non RCT	-	-	3	-	-	0	-	-	-	-	-	3
NCRN197	RCT	-	-	6	-	-	0	-	-	-	-	-	6
NCRN611	RCT	-	-	-	1	-	-	-	5	-	-	-	6
Select-d	RCT	-	-	-	-	-	-	-	-	-	-	1	1
SCORAD III	RCT	-	-	9	-	-	-	-	-	-	-	0	9
TVT	RCT	-	-	-	-	0	-	-	-	-	-	-	0
<b>Total</b>		<b>0</b>	<b>0</b>	<b>18</b>	<b>1</b>	<b>0</b>	<b>4</b>	<b>0</b>	<b>9</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>33</b>

## 9. The Pathway Board

### 10.1 Formation of the Board

The principle of Manchester Cancer Pathway Boards is that they should be professionally and institutionally representative, yet small and manageable in size. To help Pathway Clinical Directors form institutionally representative Boards the Manchester Cancer central team sought nominations from trusts for their representative(s) on 16 of the 20 Pathway Boards. Nominations were not sought for Children's, Sarcoma, Palliative Care and Early Diagnosis as alternative arrangements were necessary in these areas.

Palliative Care nominations were identified by the Pathway Director and include some members from the SCN Greater Manchester Palliative and End of Life Care Advisory Board. This ensures joint working and reduces potential duplications in efforts. This joint effort continues with back-to-back meetings to reduce time out of clinical duties and encourages engagement. The list of membership is highlighted in section 10.2; during the last meeting in July members identified General Practice representation is the gap in membership and seek to identify nominations. Named outcome leads will be identified in the September meeting.

## 10.2 Membership

Name	Role & Trust
Carole Mula	Pathway Director
Dr Kimberley Steel Dr Barbara Downes	Consultants in Palliative Medicine <b>Bolton FT</b> and <b>Bolton Hospice</b>
Dr Ashique Ahamed	Consultant in Palliative Medicine <b>CMFT</b>
Dr Iain Lawrie	Consultant Lead Clinician for Specialist Palliative and End of Life Care, <b>PAT</b>
Wendy Allen	Patient Lead
Dr David Waterman	Consultant in Palliative Medicine <b>Stockport NHS Foundation Trust</b>
Dr Hayes Margaret	Macmillan CNS Team Leader Palliative Medicine, <b>Tameside</b>
Dr Sophie Harrison	Consultant in Palliative Medicine <b>UHSM</b>
Dr Jenny Wiseman	Consultant in Palliative Medicine <b>WWL FT</b>
Ursula Haworth	AHP, <b>CMFT</b>
Dr Phil Lomax	Consultant in Palliative Medicine, <b>SRFT</b> and Medical Director St Ann's Hospice
Dr Stephanie Gomm	Consultant in Palliative Medicine <b>SRFT</b>
Julie Whitehead	Pharmacist, <b>East Cheshire NHS Trust</b>
Jennifer Gallagher	Macmillan Palliative Care team Leader <b>WWL FT</b>
Natasha Subherwal	Pharmacist, <b>East Cheshire NHS Trust</b>
Dr Jane Younger	Consultant in liaison Psychiatry, <b>Christie</b>

## 10.3 Meetings

The board have met on two occasions since the formation of Manchester Cancer. The first meeting held in May focused on scene setting and agreeing the Terms of Reference including discussions on the future work programme. The meeting in July, encouraged members to focus on the work programme for the coming year; this included a discussion on the specific details of the proposed service mapping.

## 11 Progress and challenges to date

### Progress

- Agreed joint working arrangement between SCN Palliative and End of Life Care Advisory Group and the Manchester Cancer Palliative Care Board.
- Established a multi-professional pathway board representing the geographical area.
- Undertaking a mapping / baseline of services against national standards.
- Undertaking a survey to understand oncology provider perceptions of specialist and generalist palliative care.
- Palliative Research in Manchester (PRiMA) has developed strong links within The University of Manchester and with a few NHS and voluntary organisations to support and develop palliative care research in the city and across the region.
- Chief Investigators and commercial companies designing international, multi-centre trials relating to palliative care are increasingly approaching organisations in Manchester to seek their involvement (e.g. The Christie and The Pennine Acute Hospitals NHS Trust).

### Challenges

- Palliative expands across the whole cancer pathway and across all the disease groups; the demand for palliative care will rise due to the increase in cancer prevalence; the need for proactive integration of palliative care for patients receiving systemic anti-cancer therapies; the rapidly ageing population; increasing multiple co-morbidities.
- Influencing the development of integrated clinical data systems to include palliative and end of life care.
- The implementation of the electronic palliative care coordination system (EPaCCS) is at variable stages across Manchester Cancer. Established EPaCCS are beginning to show improvements in quality of care with the potential to generate efficiency savings through reductions in unwanted and inappropriate interventions and emergency admissions to hospital.
  - Provision of 7 a day face to face specialist palliative care service and 24/7 access to specialist palliative care advice.
  - Recruitment of patients in clinical trials.
  - Establishing an effective infrastructure for palliative and end of life care research and education.

- Lack of dedicated time and resource for clinical professionals to effectively engage in clinical research.
- Lack of an academic department of Palliative Medicine within Manchester which impacts on engagement in clinical research and education.

## 12 Vision and objectives

Every person affected by cancer and their relatives/carers in Manchester Cancer will have their needs assessed, their wishes and preferences discussed where appropriate, and an agreed set of actions reflecting the choices they make about their care. This will include those people, receiving anti-cancer treatments, living with cancer and those in the advanced stages of the disease. Every person will be offered a range of physical, emotional, spiritual and social support to improve their quality of life.

The Board will promote the implementation of the Electronic Palliative Care Co-ordination System (EPaCCS) for End of Life Care (EoLC) to improve the recording, communication and coordination of care thereby providing better quality care for patients.

To map the integration of palliative care (generalist and specialist) service provision into oncology care in collaboration with the SCN and the Living With and Beyond pathway board. The findings will provide options on the way forward in achieving national standards.

## Appendix 1: Glossary

### **End of Life Care**

Care which helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

*Source: National Council for Palliative Care 2006*

### **General(ist) Palliative Care**

Services in all sectors providing day-to-day care to patients with advanced disease and their carers, designed to alleviate symptoms and concerns, but not expected to cure the disease.

*Adapted from: Improving Supportive and Palliative Care for Adults with Cancer, 2004*

### **Hospice care**

A hospice is not just a building; it is a way of caring for people. Hospice care aims to improve the lives of people who have a life-limiting or terminal illness, helping them to live well before they die. Hospice care not only takes care of people's physical needs, but looks after their emotional, spiritual and social needs as well. It also supports carers, family members and close friends, both during a person's illness and during bereavement.

<http://www.helpthehospices.org.uk/about-hospice-care/what-is-hospice-care/>

### **Palliative care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

*Source: World Health Organisation 2003*

### **Specialist Palliative Care**

Specialist palliative care is the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support...

*Source: Tebbit, National Council for Palliative Care, 1999*

### **Supportive care**

This is care which helps people with cancer and other life-threatening illnesses and their families to cope with the disease and its treatment throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

*Adapted from: Improving Supportive and Palliative Care for Adults with Cancer 2004*

## Appendix 2 – Pathway Board Terms of Reference

### Palliative Care Board

#### Terms of Reference

These terms of reference were agreed on 16<sup>th</sup> June 2014 by Carole Mula, Pathway Clinical Director for Palliative Care, and Mr David Shackley, Medical Director of Greater Manchester Cancer Services, on behalf of the Greater Manchester Cancer Services Provider Board. The terms of reference will be subject to future review.

#### 1. The Palliative Care Board

- 1.1. The Palliative Care Board is a cancer and palliative care specific board with responsibility to improve patient care and experience for local people across Greater Manchester and areas of Cheshire (a catchment population of 3.2 million). This area is synonymous with the old Greater Manchester and Cheshire Cancer Network area.
- 1.2. The Board is led by a Pathway Clinical Director and is formed of a multidisciplinary team of clinicians and other staff from all of hospital trusts that are involved in the delivery of Cancer and Palliative Care in Greater Manchester. The Board also has membership and active participation from primary care, community services, the voluntary sector and patients' representatives.
- 1.3. The Palliative Care Board reports into and is ultimately governed and held to account by Manchester Cancer Provider Board.
- 1.4. The Palliative Care Board will work closely with the Greater Manchester Palliative Care Strategic Clinical Network to ensure a collaborative approach to improve the quality of Palliative Care in Greater Manchester.

#### 2. Greater Manchester Cancer Services Provider Board

- 2.1. The Manchester Cancer Provider Board is responsible for the service and clinical delivery arm of Manchester Cancer, Greater Manchester's integrated cancer system. Manchester Cancer has two other arms: research and education (see appendix for the structure of Manchester Cancer).
- 2.2. The Provider Board is independently chaired and consists of the Chief Executive Officers of the ten acute hospital trusts in the Greater Manchester area:
  - Bolton NHS Foundation Trust
  - Central Manchester University Hospitals NHS Foundation Trust
  - East Cheshire NHS Trust
  - Pennine Acute NHS Trust
  - Salford Royal NHS Foundation Trust

- Stockport NHS Foundation Trust
- Tameside Hospital NHS Foundation Trust
- The Christie NHS Foundation Trust
- University Hospital of South Manchester NHS Foundation Trust;
- Wrightington, Wigan and Leigh NHS Foundation Trust;

2.3. The Provider Board regularly invites representatives of commissioners, the Strategic Clinical Network, and Manchester Cancer to its meetings.

### 3. Purpose of the Palliative Care Board

3.1. The purpose of the Board is to improve palliative care for patients on the various Greater Manchester Cancer Care pathways. Specifically, the Board aims to put patients at the centre of care, and improve patient and carer experience. The Board will represent the interests of local people with cancer, respecting their wider needs and concerns. It is the primary source of clinical opinion for cancer and palliative care on this pathway for Manchester Cancer Provider Board and Greater Manchester's cancer commissioners.

3.2. The Board will communicate with and work closely with the Greater Manchester Palliative and End of Life Care Strategic Clinical Network (P&EOLC SCN) Advisory Group. This will ensure a better understanding of the key issues and challenges across Greater Manchester, promote two-way communications, exchange of opinions / information and minimise duplication of work.

3.3. The Board will gain a robust understanding of the key opportunities to improve outcomes and experience by gathering and reviewing intelligence about Palliative Care. It will ensure that objectives are set, with a supporting work programme that drives improvements in clinical care and patient experience. This work programme will be aligned with the SCN programme for palliative care.

3.4. The Board will also promote equality of access, choice and quality of care for all patients within Greater Manchester, irrespective of their individual circumstances. The Board will also work with cancer commissioners to provide expert opinion on the design of any commissioning pathways, metrics and specifications.

### 4. Role of the Board

The role of the Palliative Care Board is to:

4.1. Represent Manchester Cancer Services professional, patient and carer community relating to palliative care.

4.2. Identify specific opportunities for improving patient and carer outcomes and experience and convert these into agreed objectives and a prioritised programme of work.

4.3. Gain approval from Greater Manchester's cancer commissioners and Manchester Cancer Provider Board for the programme of work and provide regular reporting on progress.

- 4.4. Collaborate with the Greater Manchester P&EOLC SCN on the programme of work including review of outcomes, identification of new service developments and receive and provide regular reporting on progress.
- 4.5. Design and implement new services for patients where these progress the objectives of commissioners and Greater Manchester Cancer Services, can be resourced, and have been shown to provide improvements in outcomes that matter to patients.
- 4.6. Ensure that treatment guidelines are agreed and followed by all teams in provider trusts, and are annually reviewed.
- 4.7. Ensure that all providers working within the Board collect dataset measures to a high standard of data quality and that this data is shared transparently amongst the Board and beyond.
- 4.8. Promote and develop research and innovation in palliative care, and have agreed objectives in this area.
- 4.9. Monitor performance and improvements in outcomes and patient experience via a scorecard, understanding variation to identify areas for action.
- 4.10. Escalate any clinical concerns through provider trusts.
- 4.11. Highlight any key issues that cannot be resolved within the Board itself to the Medical Director of Greater Manchester Cancer Services for assistance.
- 4.12. Ensure that decisions, work programmes, and scorecards involve clearly demonstrable patient participation.
- 4.13. Share best practices with other Pathway Boards within Manchester Cancer Services.
- 4.14. Contribute to cross-cutting initiatives (e.g. work streams in living with and beyond cancer and early diagnosis).
- 4.15. Discuss opportunities for improved education and training related to palliative care and implement new educational initiatives.
- 4.16. Develop an annual report of outcomes and patient experience, including an overview of progress, difficulties, peer review data and all relevant key documentation. This report will be published in July of each year and will be the key document for circulation to the Provider Board. A template for this report is available so that all Pathway Boards complete the report in a similar manner.

## 5. Membership principles

- 5.1. All member organisations of Greater Manchester Cancer Services will have at least one representative on the Board (at a minimum the clinical lead for specialist palliative care) unless they do not wish to be represented.

- 5.2. Provider trusts not part of Manchester Cancer Services can be represented on the Board if they have links to Palliative Care and Cancer across Greater Manchester this includes Community providers and hospices.
- 5.3. All specialties and professions involved in the delivery of care will be represented.
- 5.4. The Board will have at least one patient or carer representative within its membership
- 5.5. One professional member of the Board will act as a Patient Advocate, offering support to the patient and carer representative(s).
- 5.6. The Board will have named leads for:
  - Acute oncology
  - Brain and CNS
  - Breast
  - Colorectal
  - Gynaecology
  - Haemato-oncology
  - Head and Neck
  - Hepato-pancreato-biliary
  - Living with and beyond cancer ('survivorship')
  - Lung
  - Oesophago-gastric
  - Radiotherapy
  - Sarcoma
  - Skin
  - Systemic therapies
  - Teenage and Young Adult
  - Urological
  
  - Specialist nursing
  - AHP
  - Psycho-oncology
  - Research
  - Education
  - Data collection (clinical outcomes/experience and research input) (EPaCCS)
- 5.7. It is possible for an individual to hold more than one of these posts. The Clinical Director is responsible for their fair appointment and holding them to account.
- 5.8. These named leads will link with wider Manchester Cancer Boards for these areas where they exist.
- 5.9. All members will be expected to attend regular meetings of the Board to ensure consistency of discussions and decision-making (meeting dates for the whole year will be set annually to allow members to make arrangements for their attendance).

- 5.10. A register of attendance will be kept: members should aim to attend at least 5 of the 6 meetings annually and an individual's membership of the Board will be reviewed in the event of frequent non-attendance.
- 5.11. Each member will have a named deputy who will attend on the rare occasions that the member of the Board cannot.

## 6. Frequency of meetings

- 6.1. The Palliative Care Board will meet every two months.

## 7. Quorum

- 7.1. Quorum will be the Clinical Director plus five members of the Board or their named deputies.

## 8. Communication and engagement

- 8.1. Accurate representative minutes will be taken at all meetings and these will be circulated and then validated at the next meeting of the Board.
- 8.2. All minutes, circulated papers and associated data outputs will be archived and stored by the Clinical Director and relevant Pathway Manager.
- 8.3. The Board will design, organise and host at least one open meeting per year for the wider clinical community and local people. This meeting or meetings will include:
- An annual engagement event to account for its progress against its work programme objectives and to obtain input and feedback from the local professional community
  - An annual educational event for wider professionals and interested others to allow new developments and learning to be disseminated across the system
- 8.4. Representatives from all sections of Manchester Cancer professional body will be invited to these events, as well as patient and public representatives and voluntary sector partners.
- 8.5. An annual report will be created and circulated to the Medical Director of Manchester Cancer Provider Board by 31<sup>st</sup> July of each calendar year.
- 8.6. The agendas, minutes and work programmes of the Board, as well as copies of papers from educational and engagement events, will be made available to all in an open and transparent manner through Manchester Cancer website once this has been developed.

## 9. Administrative support

- 9.1. Administrative support will be provided by the relevant Pathway Manager with the support of Manchester Cancer core team. Over the course of a year, an average of one day per week administrative support will be provided.

## Appendix 2 – Pathway Board meeting attendance

Name	Role & Trust	22nd may	8th July	25th September
Carole Mula	Pathway Director	✓	✓	✓
Kimberley Steel	Consultant in Palliative Medicine <b>Bolton FT</b>	apologies	✓	apologies
Dr Downes	Consultant at FT and <b>Bolton Hospice</b>	✓	apologies	apologies
Ashique Ahamed	Consultant in Palliative Medicine <b>CMFT</b>	✓	✓	✓
Iain Lawrie	Consultant Lead Clinician for Specialist Palliative and End of Life Care, <b>PAT</b>	apologies	apologies	apologies
Wendy Allen	Patient Lead	apologies	✓	✓
David Waterman	Consultant in Palliative Medicine <b>Stockport NHS Foundation Trust</b>	✓	✓	✓
Hayes Margaret	Macmillan CNS Team Leader Palliative Medicine, <b>Tameside</b>	✓	✓	
Sophie Harrison	Consultant in Palliative Medicine <b>UHSM</b>	✓	✓	✓
Ursula Haworth	AHP <b>CMFT</b>			✓
	Consultant in Palliative Medicine <b>WWL FT</b>	apologies	✓	apologies
Phil Lomax	Consultant in Palliative Medicine SRFT and Medical Director St Ann's Hospics	✓		apologies
Stephanie Gomm	Consultant in Palliative Medicine <b>SRFT</b>	✓		✓
Julie Whitehead	Pharmacist, <b>East Cheshire NHS Trust</b>	apologies	apologies	✓
Jennifer Gallagher	Macmillan Palliative Care team Leader <b>WWL FT</b>	✓	apologies	✓
Natasha Subherwal	Pharmacist, <b>East Cheshire NHS Trust</b>	apologies	apologies	apologies
Jane Younger	Consultant in liaison Psychiatry, <b>Christie</b>	apologies	✓	apologies

## 13 Appendix 3 – Pathway Board Annual Plan 2014/15

### Palliative Care Board Annual Plan 2014-15

<b>Pathway Director:</b>	<b>Clinical</b>	Carole Mula
<b>Pathway Members:</b>	<b>Board</b>	<p>Dr Kimberley Steel, Consultant in Palliative Medicine Bolton FT</p> <p>Dr Barbara Downes, Consultant in Palliative Medicine Bolton FT and Bolton Hospice</p> <p>Dr Ashique Ahamed , Consultant in Palliative Medicine CMFT</p> <p>Dr Iain Lawrie, Consultant in Palliative Medicine, Lead Clinician for Specialist Palliative and End of Life Care, PAT</p> <p>Wendy Allen, Patient Lead</p> <p>Dr David Waterman, Consultant in Palliative Medicine Stockport NHS Foundation Trust</p> <p>Hayes Margaret, Macmillan CNS Team Leader Palliative Medicine, Tameside</p> <p>Dr Sophie Harrison, Consultant in Palliative Medicine UHSM</p> <p>Dr Jenny Wiseman, Consultant in Palliative Medicine WWL FT</p> <p>Dr Phil Lomax, Consultant in Palliative Medicine, SRFT and St Ann’s Hospice</p> <p>Dr Stephanie Gomm, Consultant in Palliative Medicine SRFT</p> <p>Julie Whitehead, Pharmacist East Cheshire NHS Trust</p> <p>Jennifer Gallagher, Macmillan Palliative Care team Leader WWL FT</p> <p>Natasha Subherwal , Pharmacist East Cheshire NHS Trust</p>
<b>Pathway Manager:</b>		Hodan Noor
<b>Date agreed by Pathway Board:</b>		8 <sup>th</sup> July 2014
<b>Date agreed by Medical Director:</b>		
<b>Review date:</b>		

### Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	Promote the Implementation of the Electronic Palliative Care Co-ordination system (EPaCCS) for End of Life care (EoL)	<b>Patient Experience</b>
2	Mapping the integration of palliative care (generalist and specialist) service provision into oncology care. To include palliative care involvement across disease specific MDTs, education and training needs, awareness of services, systems and capacity.	<b>Improving Survival rate and patient experience</b>

## Objective 1: Electronic Palliative Care Co-ordination system

<b>Objective:</b>	<p>To support the implementation of EPaCCS in partnership with Strategic Clinical Network (SCN) and Greater Manchester Academic Health Science Network (GMAHSN) by;</p> <ul style="list-style-type: none"><li>• Host EPaCCS templates and training guidelines for primary care and secondary care on Manchester Cancer website.</li><li>• Promote to CCG Cancer Leads the development of EPaCCS and training tools available.</li><li>• Incorporate EPaCCS information as part of the suite of GP education series.</li><li>• Highlight the importance of integrating EPaCCS into the development of clinical outcomes across Manchester Cancer.</li></ul>
<b>Rationale:</b>	<p>The End of Life Care Strategy (DH 2008) identified the need to improve co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The development of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as EPaCCS) were identified as a mechanism for enabling co-ordination.</p> <p>By supporting the elicitation, recording and sharing of people's care preferences, and key details about their care, it is anticipated that EPaCCS will improve the quality of care, with provision meeting people's expressed wishes and preferences. Early findings from the South West SHA Locality Register pilot showed that the vast majority of people on the register were able to die outside of hospital, and in their preferred place of care.</p> <p>EPaCCS will contribute to increases in the quality of end of life care individuals receive by improving co-ordination and communication across sectors, ensuring that all those involved in care will be aware of the individuals wishes and preferences as recorded in Advance Care Plans (ACPs) as well as treatment care plans. They contribute to the patient Choice agenda as well as the Quality, Improvement, Productivity and Prevention (QIPP) agenda and improve patient safety by reducing harm through co-ordinated communication in standardised format to reduce the risk of inappropriate interventions.</p> <p><b><i>70% rollout of Electronic Palliative Care Coordination Systems (EPaCCS) across England (baseline 15%) (NHS Improving Quality - Our Strategic Intent March 2013)</i></b></p> <p>In the northwest a programme of work led by the Strategic Clinical Network has achieved the following;</p> <ul style="list-style-type: none"><li>• Shared common dataset</li><li>• Sharing of EPaCCS templates already built and in use in local systems</li><li>• Shared information governance (IG) documentation</li></ul>

	<ul style="list-style-type: none"> <li>Use of common approach to communicate with NWS and other shared resources</li> </ul> <p>Locally the members of the Manchester Palliative Care board meeting in May 2014 raised support for adherence and usage of EPaCCS within the Greater Manchester area as a potential programme of work for the board.</p>
<b>By (date):</b>	<p><i>What is the target date for completion?</i></p> <p>The target date for completion of the listed objectives is March 31<sup>st</sup> 2015</p>
<b>Board measure(s):</b>	<p><i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i></p> <ol style="list-style-type: none"> <li>Number of Downloads of EPaCCS training package from Manchester Cancer website</li> <li>Support SCN to achieve 70% rollout of EPaCCS</li> <li>Increase EPaCCS reporting (SCN key area 8 implementation)</li> </ol> <p>Measure 1 will be reported by Manchester Cancer, measure 2 and 3 will be reported by the CCG audits to be undertaken in 2015/16</p>
<b>Risks to success:</b>	<p><i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i></p> <p>No risks identified</p>
<b>Support required:</b>	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i></p> <p>Existing operational support.</p>

<b>Work programme</b>		
<b>Action</b>	<b>Resp.</b>	<b>By (date)</b>
SCN to shared training template with Manchester Cancer	Stephen Burrows (SCN)	31 <sup>st</sup> August 2014
Manchester Cancer to upload information on website and set up the recording of downloads	Hodan Noor (MC)	30 <sup>th</sup> September 2014
Marketing to GP cancer leads via: emails, website news and training and education events	Hodan Noor (MC) Stephen Burrows (SCN)	30 <sup>th</sup> September to March 2014
Marketing to partner organisations	Board Members	
Reporting number of downloads per quarter	Hodan Noor	31 <sup>st</sup> January 2014
Presentation to Manchester Cancer provider board	Carole Mula (MC Palliative Care board Director)	TBC

**Objective 2: Mapping of Palliative Care service provision**

<p><b>Objective:</b></p>	<p>Mapping the integration of both generalist and specialist palliative care service provision into oncology care will identify the following;</p> <ul style="list-style-type: none"> <li>• Gaps in service provision</li> <li>• Capacity issues</li> <li>• Referral criteria</li> <li>• Palliative care involvement across disease specific MDTs</li> <li>• Education and training needs</li> <li>• Awareness of services.</li> </ul>
<p><b>Rationale:</b></p>	<p>The project aims to support the National Outcomes Framework, Domain 2: Enhancing quality of life for people with long-term conditions and Domain 4: Ensuring that people have a positive experience of care.</p> <p>Palliative and end of life care involves care to all those with any advanced, progressive, incurable illness, enabling each individual to live as well as possible until they die and includes the management of pain and other symptoms and the provision of psychological, social, spiritual and practical support. In order to support patients with advanced stages of cancer, access to a range of service to improve their quality of life is required.</p> <p>The workforce involved in the delivery of general palliative and end of life care for patients with cancer is very large. The workforce includes health and social care, and voluntary staff (oncologists, doctors, nurses, allied health professionals, social care professionals etc.) employed by many different types of employers and working in a variety of settings.</p> <p>Of these, the specialist palliative care workforce is relatively small compared to the total number of health and social care professionals who deliver general palliative and end of life care. Thus it is important to map systems and processes for both general and specialist palliative care to identify priority areas for future developments in palliative and end of life care across Greater Manchester.</p> <p>Area to be addressed include:</p> <p><b>Living with Cancer pathway board sub group using longitudinal survey run twice a year.</b></p> <ul style="list-style-type: none"> <li>• oncology teams perceptions of general and specialist palliative care</li> <li>• whether clinical staff caring for oncology patients with palliative care needs, feel confident in their palliative care skills and knowledgeable</li> <li>• education and training needs in palliative care and end of life care</li> <li>• identification of those disease groups with a high symptom burden</li> </ul> <p><b>Mapping effectiveness of palliative care input into disease specific MDTs</b></p>

	<p><b>Strategic Clinical Network , Palliative and End of Life Care Advisory Group</b></p> <ul style="list-style-type: none"> <li>• Address the findings from the SCN mapping with regards to specialist palliative care services and gaps in service provision that impact of the cancer journey.</li> </ul> <p>Future developments, informed through this mapping, will impact on the quality and experience of patient care and on the health of the wider population through ensuring a skilled workforce to deliver care for people with palliative and end of life care needs, ensuring care is aligned to individual patient’s needs and preferences.</p>
<b>By (date):</b>	<p><i>What is the target date for completion? If completion is expected beyond 2014/15 what progress is expected in year?</i></p> <p>The analysis of the level of need will be determined as part of the “<i>mapping of service provision</i>” project lead by the Living With and Beyond Pathway Board and the target completion for this is November 2014 and the mapping of specialist palliative care MDT’s by the Strategic Clinical Network.</p> <p>The longitudinal survey shift and changes in awareness/perception to palliative care will be run by annually working with the Living With Cancer sub group a partnership of Palliative Care and Living with and Beyond Board.</p> <p>Using the findings, optional appraisal will be developed by the palliative board by February 2015 on the way forward.</p>
<b>Board measure(s):</b>	<p><i>Which of the Pathway Board’s key measures will show it that the objective has been met? What are the performance standards that will be expected?</i></p> <p>The key deliverable of this project will be a report on the findings and optional appraisal to approach 4 key themes (education, awareness, system, capacity)</p>
<b>Risks to success:</b>	<p><i>What factors will hinder or prevent the Board’s ability to achieve the objective? How will these risks be mitigated?</i></p> <p>No risk identified</p>
<b>Support required:</b>	<p><i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i></p> <p>Existing operational resources to collate and report findings</p>

<b>Work programme</b>		
<b>Action</b>	<b>Resp.</b>	<b>By (date)</b>
Agree final questions to incorporate in the service mapping	Board members	15 <sup>th</sup> August 2014
Link with findings from SCN mapping of Specialist Palliative Care	TBC	TBC
Longitudinal survey on awareness and perception with Living with Cancer subgroup	TBC	TBC
Analyse finding and develop optional appraisal for the way forward	Board members	December – February 2015

### **Appendix: Manchester Cancer Provider Board objectives**

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The Manchester Cancer Provider Board has identified the themes of its three key objectives. The precise wording of those objectives remains to be confirmed.

- 1. 1-year SURVIVAL:** Focus on improving 1-year pooled cancer overall survival rate, so that we halve the survival gap with the world's best (Sweden) for patients diagnosed in 2020, and approach their figures by 2025
- 2. Patient EXPERIENCE:** Achieve year-on-year improvement in patient experience aspiring to be the best performing conurbation in the National Cancer Patient Experience Survey
- 3. RESEARCH and INNOVATION:** Increase patient involvement in research (>40% by 2019) and be an international leader in developing innovation in clinical practice