

End of Life Baseline Report

(Demand & Threshold Management QIPP)

For Greater Manchester PCT Cluster

“How people die remains in the memory of those who live on”

Dame Cicely Saunders, Founder of the Hospice Movement.

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1 Executive Summary.

1.1 Introduction

End of life care is a key priority of the North West regional QIPP workstream for Demand and Threshold Management and the North West SHA in recognition that improving QIPP across the end of life care pathway will significantly support overall delivery against the £20 billion QIPP challenge by 2014/15.

The North West vision is for people to be supported to die well in the place of their choice; with a broad aim to reduce avoidable hospital admissions for patients at the end of life and to expedite discharge for end of life care patients who are admitted to hospital for emergency care.

Our population is getting older and sicker. Currently there are around 1.5 million people with long term conditions living in the North West; it is estimated this figure will be 3 million by 2030. In tandem with this, population statistics estimate that the people over the age of 65 will increase by 252% by 2050; described by Sir John Oldham as *“a Tsunami of need”*.

While end of life care requires concerted action by a range of partners, including social care, the NHS plays a central role. As such, end of life care has featured in successive NHS Operating Frameworks, with emphasis around the End of Life Care Strategy¹. The new NHS Operating Framework 2012/13² sets out a considerable challenge in terms of accelerating delivery against the QIPP challenge in year, and with a clear focus on long term conditions and integration, eg providing services closer to patients and between different sectors of care. End of life care will be a critical part of this.

This baseline report has been developed for each North West PCT cluster as a resource to support their commissioning intentions by setting out why tackling end of life care is important, outlining the critical success factors to deliver high quality end of life care and how to achieve them, data and evidence underpinning success, and identifying areas for improvement. In addition, cluster QIPP priorities, CQuIN schemes, Innovation and the contribution of local hospices are considered. The focus of this report is adults and Long Term Condition's, in line with the work priorities of the level 4 Demand and Threshold Management QIPP workstream; it does not specifically cover children or other specialist areas such as learning disabilities. However the resources developed within this report can be utilised across all areas of care.

Recommendations and the resources to support this work are provided.

1.2 Background and context.

Hospital admissions for adults in the last year of life are estimated to cost the NHS around £1.3 billion³. Savings could potentially be achieved on these hospital costs which would free up resources to provide supportive and palliative care in the community.

More than 450,000 people die in England each year and more than half of these deaths occur in hospital. Surveys identify that 66% patients would prefer to die at home. If possible, people should have the opportunity to die in a place of their choosing and unnecessary hospitalisation of the dying should be avoided whenever feasible.⁴

ONS Figures⁵ indicate most deaths occur in NHS hospitals (58%) with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere. Based on ONS figures of deaths in usual place of residence, there appears to be limited improvement in achieving a greater proportion of deaths in usual place of residence. This means that from a QIPP perspective there is a considerable opportunity for ensuring people have a better death at lower cost and one factor that could make a significant difference is the extent to which GPs are actively identifying people

approaching the end of life and putting plans in place to support them as their condition deteriorates.

The National Audit Office⁶ found that 40% of end of life care patients had no medical need to be in hospital. An analysis of hospital use by adults in the last year of life was recently undertaken by the Department of Health and shows that 32.6% of all hospital admission for adults in the last year of life occurs in the last 30 days before death¹.

Evidence recently published in the Palliative Care Funding Review⁷ estimates that between 70% and 80% of all deaths are likely to need palliative care input; for the North West this equates to around 48,485 people requiring palliative care every year, based on a mid-point of 75% against all deaths.

The changing demographics of an ageing population, longer chronic disease trajectories, and greater co-morbidity, provide further incentives to improve and expand palliative care and end of life care provision. In the North West alone, it is estimated that the number of people with long term conditions (LTC's) will double to 3 million by 2030⁸, whilst the Demos Report *Dying for Change*⁹ estimates that by 2030, the number of deaths per year will rise by 90,000 and the number of hospital deaths will be close to 60%.

The North West End of Life clinical pathway group¹⁰, in response to the Darzi NHS Next Stage Review, set out a vision and aim to reduce hospital deaths across the North West by 10% by 2012 from a 2007 baseline; in the North West in 2007, 57.8% people died in hospital whilst surveys showed that 64% of people prefer to die at home. Subsequent surveys and reviews show that little has changed. A report of local preferences and place of death by government office region showed that in the North West, 64% of people would prefer to die at home¹¹, as previously stated we know that data shows that deaths at home in the North West were 37% against an England average of 38.8%. This does show an improvement for the North West of 1.2% against the same period for the previous year. Currently, the North West ranks 9 out of the 10 SHAs in respect of % of home deaths, with significant variation between NW PCT's of the best - 43.1% and the worst - 30%.

1.3 Critical factors for success; what supports end of life care being good in your area?

End of Life Care (EoL) 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 into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support⁴. High quality community based services cost no more, and can cost less, than hospital based care. The NHS Operating Framework for 2010/11 encouraged PCTs to use resources to the best effect locally in order to provide quality end of life care, such as enable choice of place of death.¹

The North West End of Life Care Model (see appendix 2) uses a whole systems approach for all adults with a life limiting disease regardless of age and setting, moving from recognition of need for end of life care, to care after death. In order to apply the model, staff across organisations are required to understand the needs and experiences of people and their carers. The challenge for effective commissioning of end of life care therefore includes defining what constitutes end of life, calculating the associated costs and defining appropriate outcomes.

North West organisations need to put in place, and consistently apply, standards to ensure delivery of high quality services for people approaching end of life, and achieve the appropriate benefits for the NHS under QIPP.

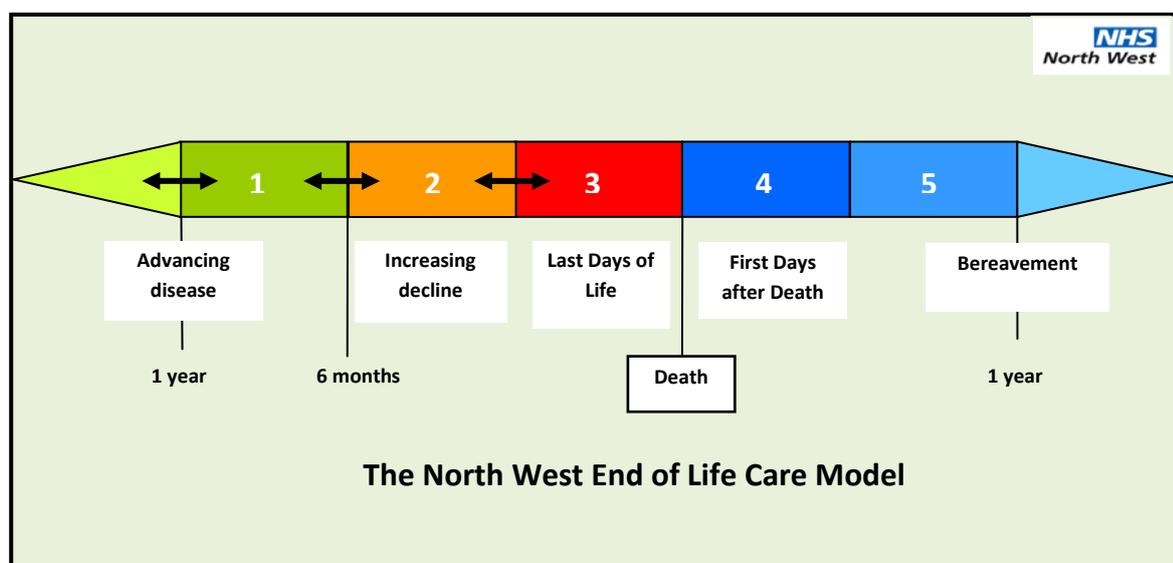
The critical factors for success are underpinned by the five key aims of the North West End of Life Clinical Pathway Group, and the End of Life Care Network service improvement programmes to support implementation of the Department of Health's End of Life Care Strategy. They are outlined in the following aims and recommendation.

1.4 Aims and Recommendations

1. **Commissioning.** Promoting Integrated Commissioning Frameworks based on the North West End of Life Care Model. Good end of life care has the NHS, local authorities, and charitable and independent sectors working together to provide a cohesive service¹⁰. The model is in full accord with the General Medical Council definition that “people are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

Figure 1. The North West End of Life Care Model. (Full description is shown at Appendix 2).



Recommendation: Clinical Commissioning Groups to identify an end of life care lead, to chair a locality group and develop a strategy to inform funding priorities.

2. **Raising awareness of death and dying and making it a normal part of conversation for both professionals and the public.** Across the North West through Network End of Life Care programmes, the national “Dying Matters” campaign has been supported with local events to raise awareness. In addition, through MPET funding, a programme “Conversations for Life” has delivered a number of community engagement events working beyond health.

Recommendation: the strategic plan should incorporate death and dying and support local implementation of the national initiative ‘Dying Matters’.

3. **Advance Care Planning** Identifying a person’s preferences regarding end of life which are included in an advance care plan and incorporate the use of nationally approved end of life care planning tools such as The Gold Standards Framework (GSF), Preferred Priorities for Care (PPC),

and Liverpool Care Pathway (LCP). The individual plan should be communicated electronically across all settings. The Information Standards Board has issued a notification¹² to have in place electronic palliative care coordinating systems (locality registers) in place supporting the co-ordination of care between GP's and other care providers, including acute hospitals and social care services by December 2013. It is unclear how areas within the NW are progressing this notification. There were a number of national pilot sites, one of which was in the North West (Salford), which gives a wealth of information and advice to support planning for and implementing a local solution.

Recommendations:

- Continued implementation of the national end of life care tools, GSF, PPC, LCP.
- Develop a model of advance care planning across the locality

4. Supportive Care Registers. Pivotal to planning in advance is identifying patients at end of life in line with the North West model and recording them on the register at practice level using the Gold Standards Framework. The framework enables care to be coordinated and the patient is reviewed systematically. There is variability on how GP practices manage this process which impacts on consistency of care. It is estimated that 1% of a GP practice population will die each year. There is a national *Find Your 1% Campaign* supported by the Royal College of General Practitioners encouraging GPs to identify their patients, through reviewing practice lists, to record them on their register and manage them proactively. The uptake for the campaign across the NW is very low.

Recommendation: implement and monitor electronic palliative care system across the locality.

5. Providing 24hr support for patients and families including access to specialist palliative care. Across the North West there has been excellent progress to provide 24hr district nursing services but this is not consistently in place across Greater Manchester. In addition, access to specialist palliative care advice and face to face review, despite being a recommendation in the NICE Improving Outcomes Guidance for Supportive and Palliative Care with an implementation date of 2009, is still not consistently in place.

Recommendation: 24hr support for patients and families including access to district nursing and specialist palliative care should be in place and compliant with the Improving Outcomes Guidance and Peer Review Measures.

6. Development and Implementation of a regional 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) policy aligned to a northern SHA cluster approach.

It is recognised that there are significant challenges of implementation; it has been the subject of national debate for some time.

Currently the North West does not have unified policy, the benefits of which include increased patient choice and satisfaction regarding end of life planning and reduction in inappropriate admissions to hospital. NHS North West recognise there is an opportunity here to exploit the work done by others and as such Dr. Mike Cheshire, Medical Director at NHS North West SHA will be leading discussions with PCT Cluster CEO's and NWSA to take this work forward through 2012.

Recommendation: implementation of a regional DNACPR policy.

7. Ensuring care is delivered through a skilled and confident work force.

MPET funding has enabled the End of Life networks to support many initiatives across the North West to promote education and training for the end of life care workforce. Priorities have been

to build confidence and capability in the care home sector to support residents to stay in their usual place of residence (their care home) and this saw the successful development of the North West “Six Steps to success” programme for care homes. The national GSF programme for care homes continues to be implemented also. Engagement with primary care has been crucial. Education and training in palliative care, symptom control and advance care planning has been delivered to GPs across each network and advanced communication skills training has been made available to staff working with patients at end of life.

Recommendation: Each locality strategy should include a plan for training and education of the health and social care workforce.

8. Promote the use of the NICE End of Life Care Quality Standards and the End of Life Care strategy quality markers and measures for end of life care.

Recommendation: organisations delivering end of life care should meet the NICE quality standards.

The NICE Quality Standard for End of Life Care for Adults¹³, published November 2011, further endorses all the above priorities for delivering high quality care for adults approaching the end of life and the experience of their families and carers. It states:

“The quality standard for end of life care for adults requires that services are commissioned from and coordinated across all relevant agencies, including specialist palliative care, and encompass the whole end of life care pathway. An integrated approach to provision of services is fundamental to the delivery of high-quality care to people approaching the end of life and their families and carers.”

2.0 What does this mean for Greater Manchester PCT Cluster?

2.1 Introduction

The graphs below shows the population projections by age and sex, which when considered against the data for hospital deaths, deaths in usual place of residence, and peoples preferences for place of death, presents a challenging picture for commissioners and providers of end of life care. The data for deaths is specifically shown across five LTC priority areas of the North West level 4 QIPP workstream for Demand & Threshold Management, for the purposes of emphasising the opportunity to coordinate work in line with the National QIPP programmes for end of life and LTC, and the North West Advancing Quality Alliance. Based on calculations taken from the palliative care funding review 2011⁷, it is estimated that on average, in the North West, 48,485 people will require palliative care every year.

Data is also presented to show hospital deaths occurring within 3, 4-7, and 8+ days of admission. In terms of QIPP, from the perspective of quality and cost, significant benefits could be achieved by addressing the long lengths of stay.

Looking at the deaths by disease group provides opportunities to combine effort and actions across multiple projects/campaigns, eg national end of life care programme and LTC QIPP.

Information published in the Palliative Care Funding review estimates that hospital admissions in the last year of life for adults cost the NHS around £1.3 billion with potential to make savings on these costs against a QIPP estimate of £3000 per hospital death.

Further analysis to estimate the potential QIPP opportunity at PCT cluster level is being prepared and will follow this baseline report.

Figure 1. Greater Manchester cluster: population projections by age and sex.

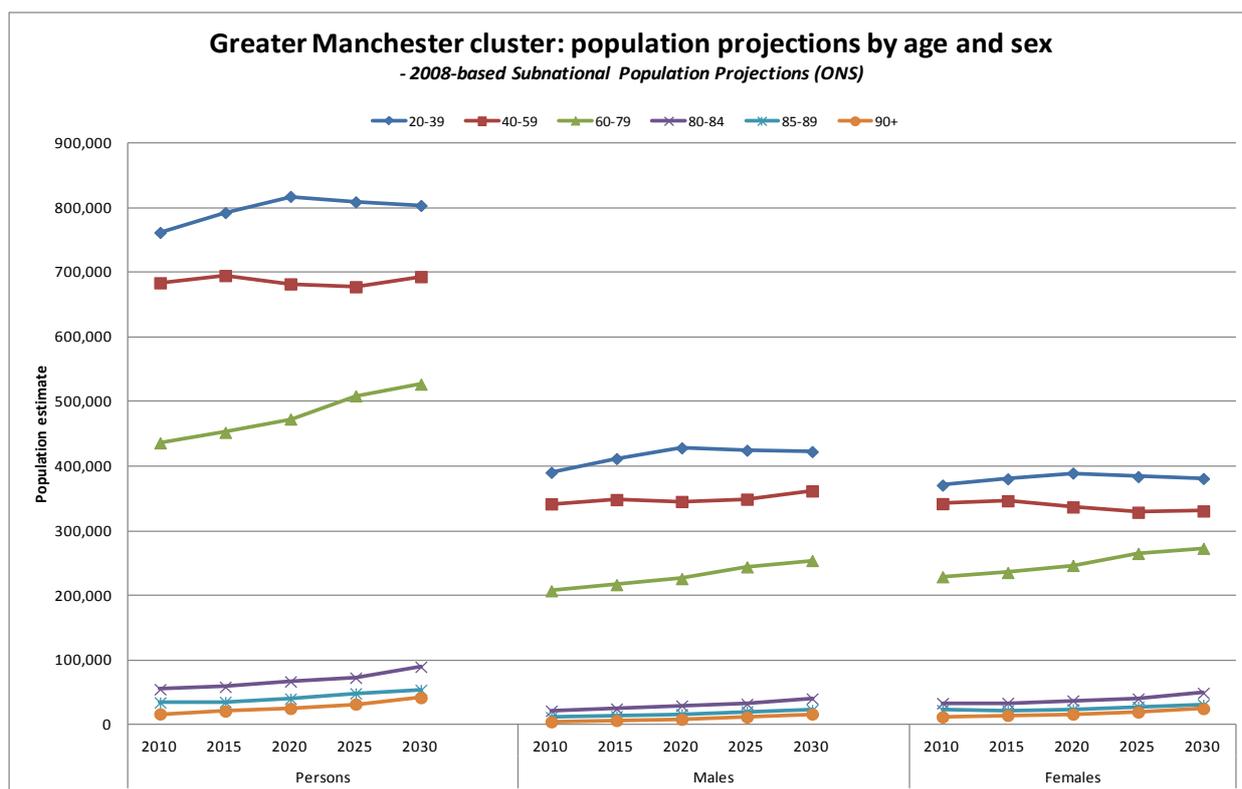
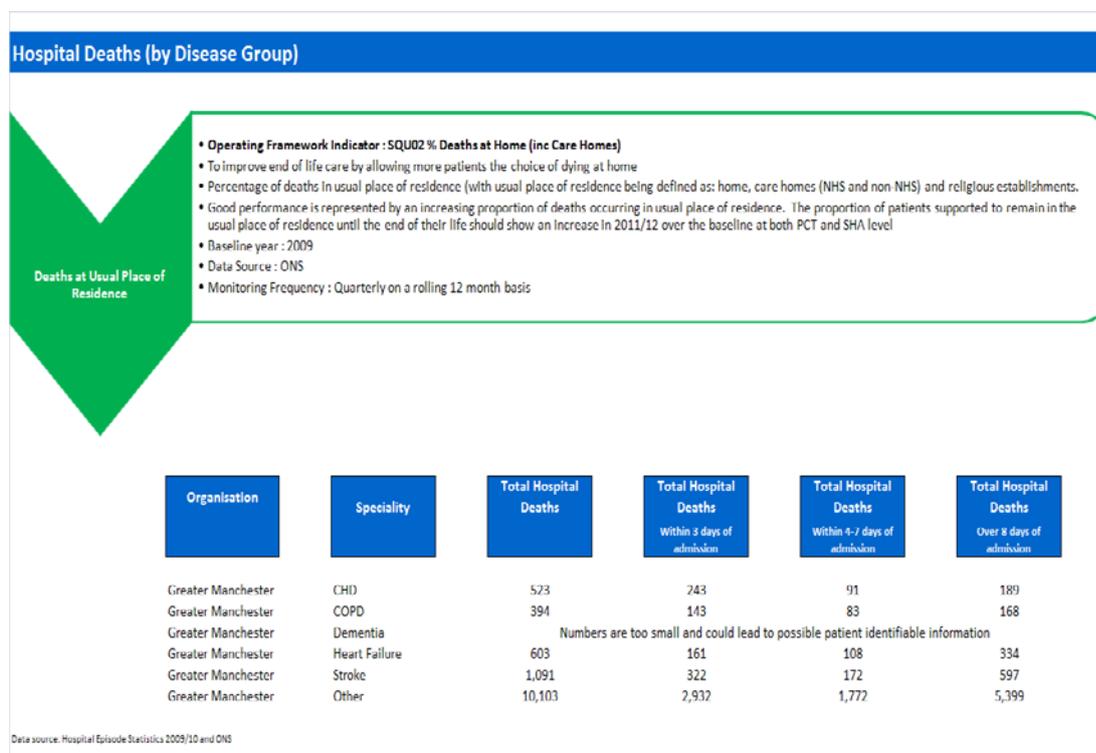


Figure 2. Hospital Deaths by disease group



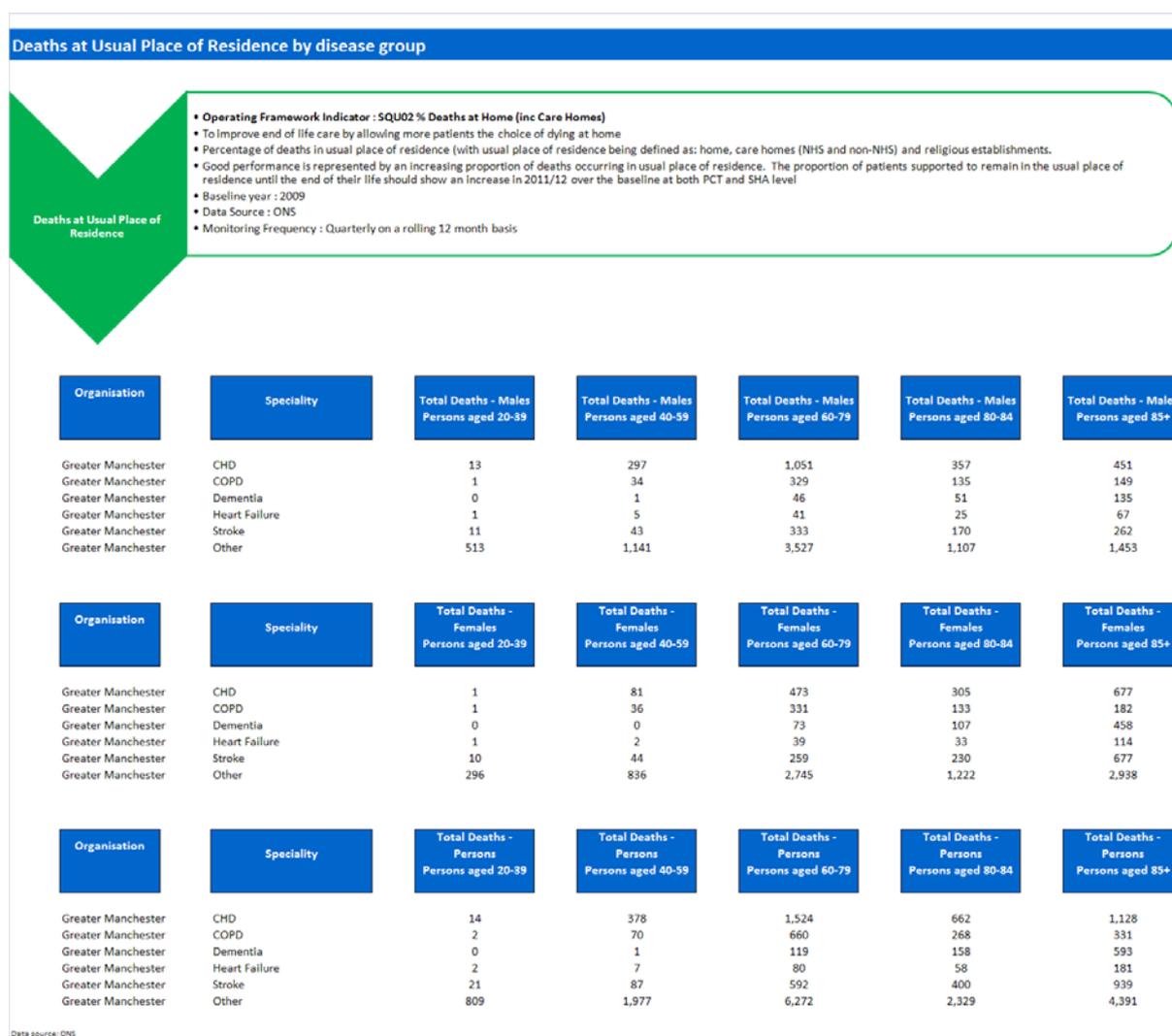
The text above is data that relates to hospital deaths which has been drawn from the Hospital Episodes Statistics (HES) for the year 2009/10. We have used this data so that it is consistent with the deaths in usual place of residence data (which follows) as 2009/10 is the most current annual published data for that dataset. Both sets of figures represent a subset of the total number of deaths for that year.

The question we should be asking ourselves is “were the hospital deaths in the appropriate setting or could those patients have had a better quality of death and died in their usual place of residence?” In essence we need to ensure that everyone has that choice and that even though someone is dying, that they are their families experience is as good as it can be at that time. The data shows that most deaths in hospital occur 8 days after admission; should those patients have remained in hospital or was there a discharge package that could have been put in place to allow that patient to die at their place of choice, i.e. their own home.

The data that follows relates to deaths in the usual place of residence and although the numbers look reasonably high, they should be placed in context. For the Greater Manchester Cluster they represent the 33% of all deaths who died in their usual place of residence throughout 2009/10.

Both data sets indicate that there is still a lot of work that needs to be done to ensure that our patients die with dignity in their place of choice.

Figure 3. Deaths at usual place of residence by disease group



Full data for figures 2 and 3 across the North West is shown at appendix 3 and 4.

2.2 What do people want?

A fundamental strand of high quality end of life care is understanding a person’s preferences for where they want to spend their last days of life. Research published by Cicely Saunders International¹¹, shows the gap between preferences and reality for place of death and provides a

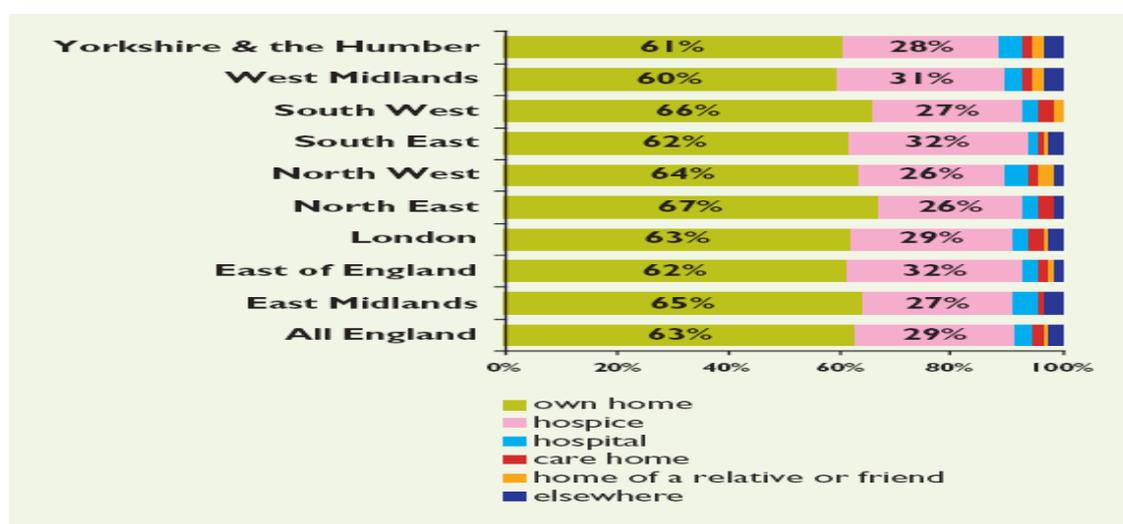
real opportunity for commissioners and providers to target improvements to support people through better care wherever they want to be at the end of life.

As previously stated, and illustrated in the figures shown below, the North West has some way to go to reduce the number of deaths in hospital and improve the number of deaths in preferred place/usual place of residence. 64% of people in the North West have identified home as their preferred place against a Greater Manchester average of 33.6% deaths in usual place of residence (see Figure 7).

Overall, the preferred place of death for the majority of people across all age groups is home or hospice, with slight variations as people get older. This is especially significant when looking at service provision now and for the future in the context of an ageing population.

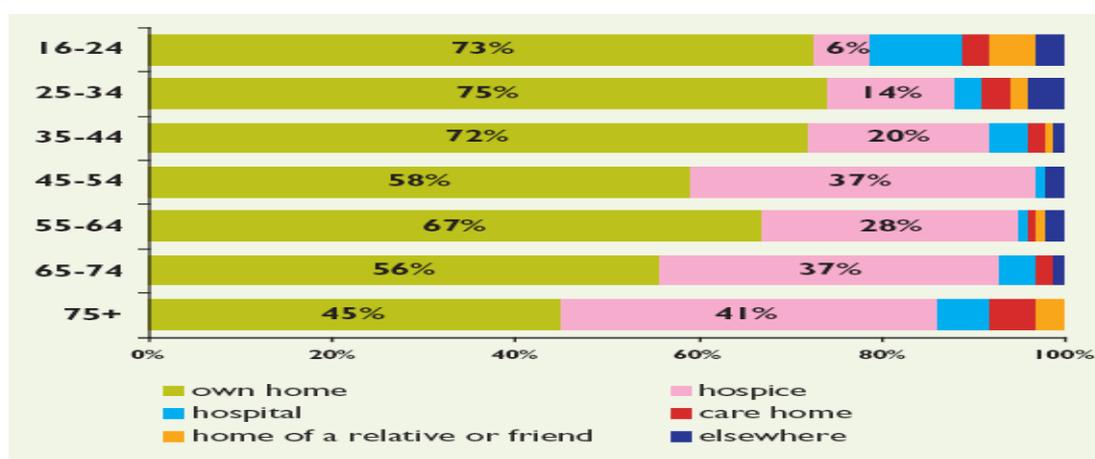
The fact that the data shown in Figures 4,5 & 6 is at regional level should not deflect from the impact of the message as most boundaries between GOR and PCT boundaries across the North West are co-terminus. In addition these boundaries will remain mostly unchanged at PCT Cluster level. [Figures 4,5, and 6 shown by kind permission of Barbara Gomes at Cicely Saunders Institute].

Figure 4. Most preferred place of death by Government Office Region



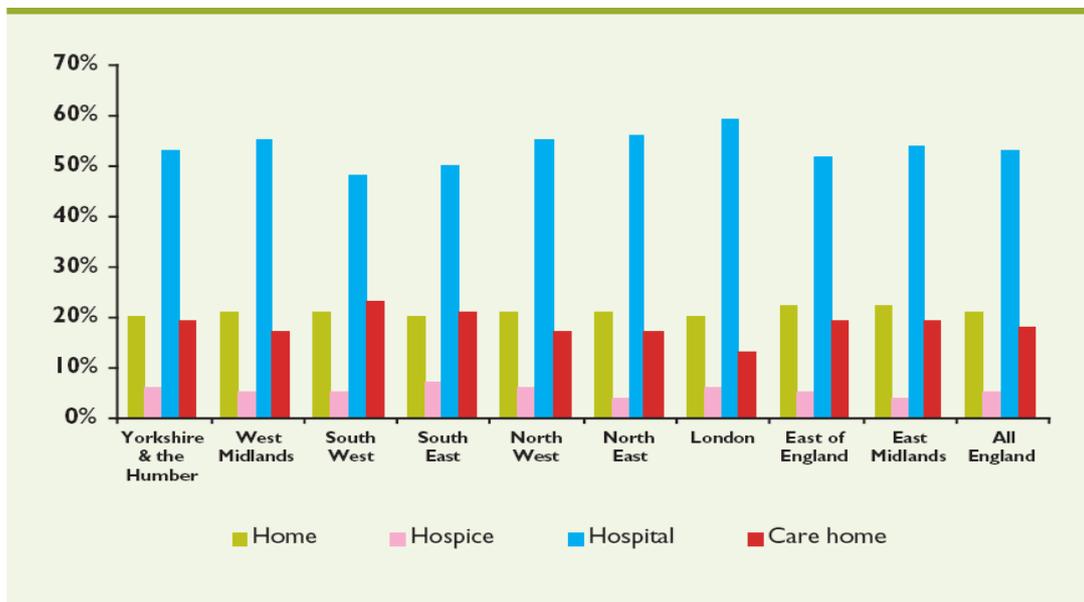
There were no significant geographical differences (Chi² test=21.123; p-value=0.994).

Figure 5. Most preferred place of death by age group



Age differences were statistically significant (Kruskal-Wallis test=43.287; p-value<0.001).

Figure 6. Place of death by GOR 2010



2.3 PCT cluster spend.

The case for change in terms of the growing needs of a population requiring end of life care, delivering high quality end of life care as determined by the critical success factors previously described, and set against a backdrop of tightening financial constraints, sets out a significant challenge to the NHS and its partners. The NHS has an unrelenting need to reduce unscheduled admissions and re-admissions, coupled with a steady reduction in the number of hospital beds in order to deliver the right care, right place, right person, right time pledge for quality healthcare; and yet the Palliative Care Funding review 2011 described an estimated growing need in the number of hospital or other beds required to meet the growing number of deaths year on year. This potentially presents a conundrum for commissioners and providers alike in terms of investment and spend required. Coupled with what people say they want and what they get, ie death in their preferred place, there is a significant gap with too many people still dying in hospital.

Table 1 below shows spend across Greater Manchester (GM) PCT Cluster, published in the Department of Health's monitoring of investment and expenditure in end of life care 2010/11. Has this level of investment and spend delivered the outcomes for high quality end of life care for the population of Greater Manchester?

Table 1. Department of Health's monitoring of investment and expenditure in end of life care 2010/11

GREATER MANCHESTER PCT CLUSTER					
PCT	New investment	Expenditure on specialist palliative care		Breakdown of investment classified as 'other'	£
	£	SPC spend £	Other declared spend £		
Aston, Leigh & Wigan	271,000	1,338,851	928,299		
Bolton	52,000	1,224,304	0		
Bury	170,000	1,183,000	0		
Heywood, Middleton & Rochdale	232,000	1,420,000	0		
Manchester	10,000	1,846,888	0		
Oldham	107,000	1,637,800	81,000	Citizen Advice	26,000

				Bureau	
Salford	177,000	1,319,000	120,000		
Stockport	0	1,323,976	0		
Tameside & Glossop	76,300	1,178,400	39,100	GP Facilitator	29,000
Trafford	95,000	1,584,000	0		
Total	1,013,300	14,056,219	1,168,399		55,000
Cheshire & Wirral Cluster	1,133,085	7,797,125	1,075,600		
Cumbria Cluster	234,000	2,642,000	0		
Lancashire Cluster	1,140,223	9,658,631	878,012		58,013
Merseyside Cluster	1,138,366	19,504,057	2,555,343		346,366

NB; not all 'other' spend is declared. Access to the full report is here

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_130336

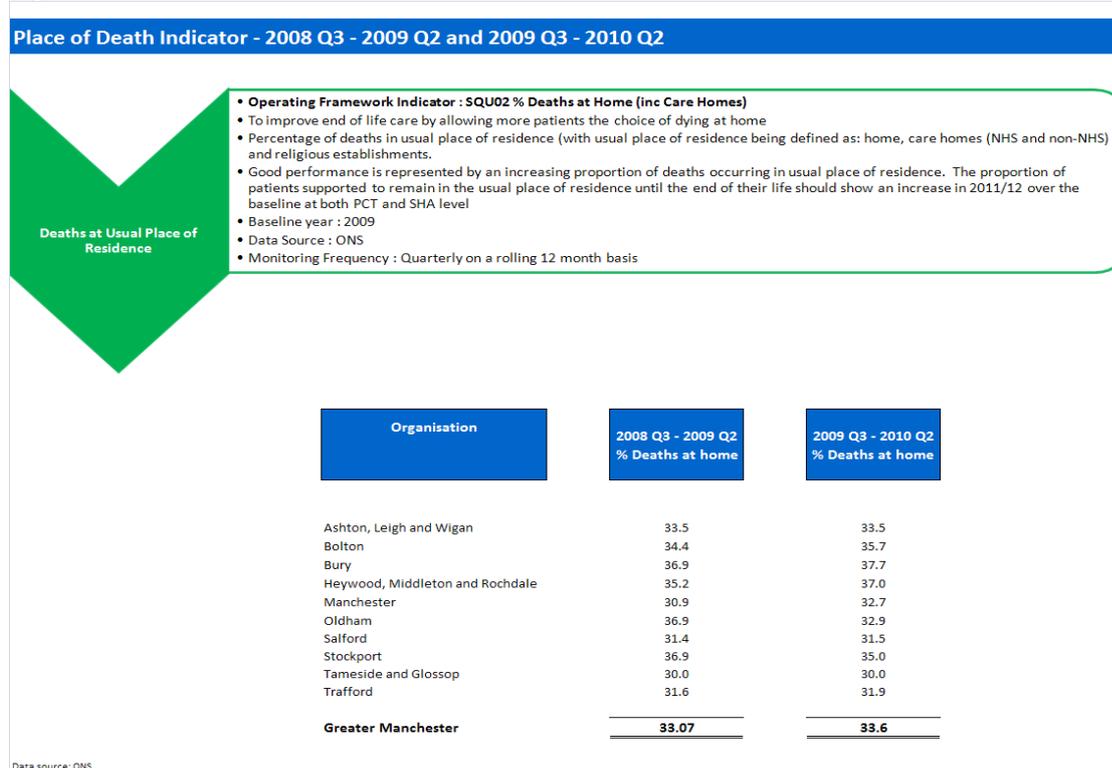
2.4 What does end of life care look like in your area?

The key performance indicators identified by the national end of life care programme are:

- % deaths in the usual place of residence, including care homes
- Reduced length of stay in hospital on final admission
- Reduce the average number of unplanned admissions in the last 12 months of life. Current estimates suggest an average of 3.6 unplanned admissions in the last 12 months of life which can cost approximately £2800 - £3400 for each episode. *(The costings are quoted from the National End of Life QIPP workstream and are based on the findings of modelling work done by six sites around the country).*

The national indicator and performance measure for improvement is the number of deaths in usual place of residence. Data for Greater Manchester is shown in figure 7 below.

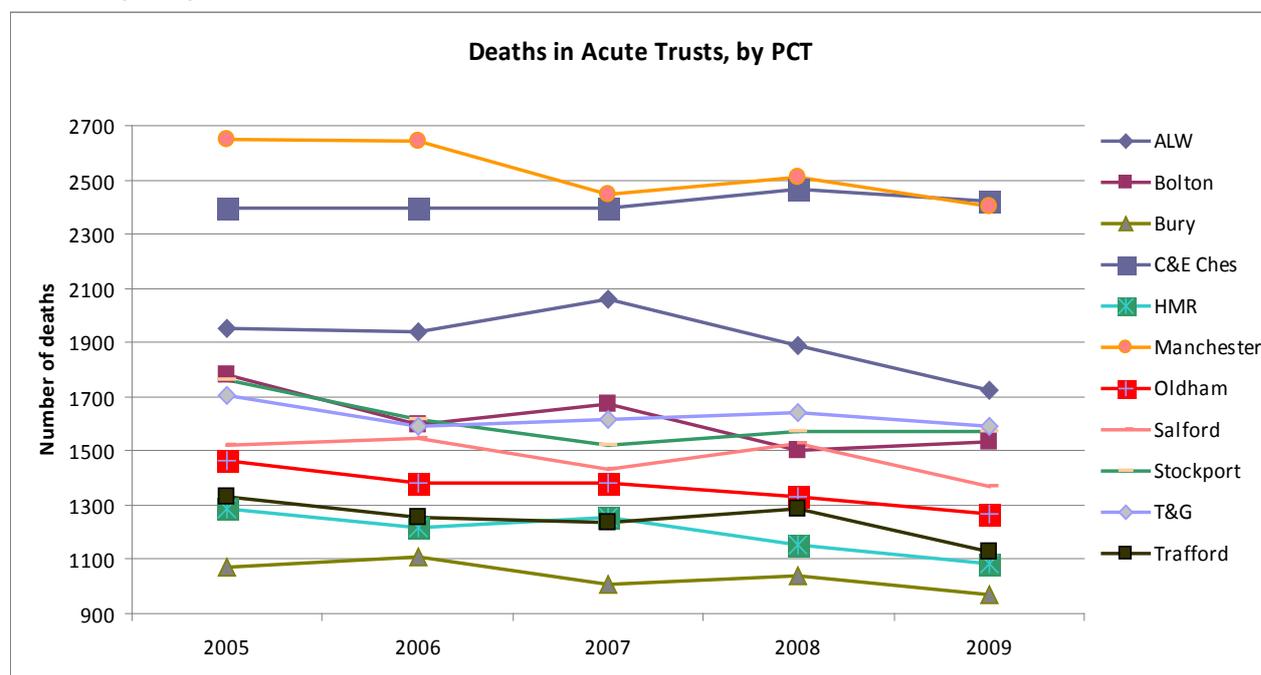
Figure 7. Place of death indicator – 2008 Q3 – 2009 Q2 and 2009 Q3 – 2010 Q2



(Full data for Place of Death Indicator across the North West is shown at appendix 5)

There is considerable variation between Greater Manchester PCTs 33.6% against an England average of 38.8%⁵. However, the commitment and work to improve quality and services for end of life care across all localities is reflected in steady reduction in hospital deaths as shown in the graph below¹⁴

Figure 8. Deaths in Acute Trusts by PCT 2005 – 2009. Source: NHS Northwest– Office of National Statistics (2011)⁵



2.5. What you have said you are going to do; QIPP/CQuIN.

End of life care features in the majority of GM PCT QIPP plans with differing priorities in each PCT area. Collectively across the cluster, the aims are aligned to the critical success factors identified in the executive summary. Perhaps the challenge in 2012/13 is joining up the different priorities to make a collective impact.

In terms of quality levers and incentives GM PCTs are using CQuIN to help them deliver good quality end of life care. Specific organisations that have end of life as a local indicator in their CQuIN plans and their aims are:

- Trafford PCT – increase number of records of patients on end of life care pathway and verification of death documentation from 46% to 75%.
- Tameside & Glossop – Improving quality of end of life through NHS NW end of life assessment for quality toolkit – each area must have progressed to level 4 by Q4 March 2011. Improve end of life pathway for patients
- NHS Salford – Improve number of people who die at home and were commenced on the care of the dying pathway. Improve number of patients on end of life pathway offered personalised plan.
- NHS Ashton Leigh & Wigan and ALW Community Health – To support patients to die in their chosen place of death. 100% of patients on end of life care pathway as their chosen place of death documented on their care plan.
- University of SM FT – Improve end of life care (of expected deaths in hospital on Liverpool Care Pathway in order to reduce deaths in hospital by 10%
- NHS Oldham (Pennine Acute) – Ensure Liverpool Care Pathway available on 100% of wards
- Oldham Community Health Services – 100% of relevant patients receiving end of life care are cared for using the Liverpool Care Pathway.

- Christie FT – Improve the standards of care along the end of life care pathway – 100% relevant dying patients are managed using Liverpool Care Pathway.

What can be learned from the GM PCT/cluster QIPP priorities and incentives applied in 2011/12, e.g. CQuIN schemes, and how will this translate into commissioning support for the new commissioning groups through 2012/13?

In terms of innovation; £5000 Regional Innovation Funding (RIF) awarded to Greater Manchester and Cheshire Cancer Network (End of Life Care Team) to spread best practice in end of life care for patients with dementia by developing specific tools for GP's. These tools are to be used by GP's to reduce inappropriate admissions and increase the number of people dying outside hospital settings. Although this RIF project is still a work in progress, the tools will be able to be adapted, with minimal modifications, for other staff groups. Full information is available here http://www.advancingqualityalliance.nhs.uk/document_uploads/Case_Studies/Kim%20Wrigley%20Sharing%20EOL%20Care_cc537.pdf

3.0 What resources are available to support you locally, now and in the future?

There are many resources, including opportunities for collaborative working with/learning from other key programmes and stakeholders for improving the quality of end of life care in the North West. Some of the most significant, currently available, are featured here.

3.1 End of Life Care Service Improvement Programme

The North West was instrumental in developing ELQUA which is a tool for self assessing, on an organisational basis, compliance with the quality markers. A number of organisations have used the tool and built their own local operational plan, including quality indicators for commissioning, based on the self assessment.

The End of Life Care programme managed by the Greater Manchester & Cheshire Cancer Network; Mersey & Cheshire Clinical Network and Cumbria & Lancashire End of Life Network are service improvement programmes linked to the National End of Life Care team. The programme objectives are to:-

- Ensure better treatment through promoting the use of the North West End of Life Care Model.
- Care to be delivered in appropriate settings through advance care planning and the use of the nationally approved EoLC tools in all care settings and disease groups.
- Build capability and capacity for health and social care professionals, voluntary and charitable organizations and the general public so death and dying will be a normal part of conversation and care planning.
- Develop robust information at Network level to support the commissioning of end of life care services.

3.2 Hospices

As shown in figure 4, 26% of people in the North West would prefer to die in a hospice and this number changes the older a person becomes, ie to 37% for people aged 65 – 74, and 41% for people aged 75 or over.

The contribution and value of hospices cannot be underestimated, and in response to a recent presentation to North West Hospices by Mike Burrows, (Chair and CEO sponsor of the North West level 4 QIPP workstream for Demand and Threshold Management), they would welcome the opportunity to work more closely with NHS Commissioning Groups on improving end of life and palliative care services for their local populations.

Across Greater Manchester and Cheshire, there are ten hospices providing 143 beds for in-patient and day care, and they are leading many excellent initiatives to improve the care and support for patients and families, some examples of which are listed below:

- St. Ann's Hospice has been collaborating with Salford Royal FT to support the implementation of its End of Life Care business case, ensuring that there is a dedicated member of staff to respond to urgent community assessments, helping to reduce unnecessary hospital admission for palliative care patients; and to support early facilitated discharge by working with SRFTs rapid discharge group.
- St. Ann's Hospice and Bury Hospice provide Hospice@Home (H@H) which provides support to patients and their families/carers enabling greater choice of place of care and place of death. The H@H teams also provide education within the Trafford area to GPs through their education forum and to the district nursing service.
- St. Ann's Hospice COPD Group – providing multidisciplinary education to patients with COPD and their carer's in recognition that this group of patients is traditionally underserved by specialist palliative care services. The aim of the programme is to reduce hospital admissions.

3.3 National LTC QIPP programme, supported by AQuA

The aims of the national LTC QIPP programme are a reduction in unscheduled admissions by 20% and reductions in hospital length of stay for people with LTC's by 25% by end March 2013. The programme, led by Sir John Oldham, is now in its operational phase of which there are three strands:

- risk profiling
- integrated care teams
- systematising self care

In the North West, 23 integrated teams are participating in the programme. The teams from Greater Manchester are:

- United League Commissioning/Bridgewater Community
- Pennine Care NHS Foundation Trust-Oldham COG/HMR / Middleton & Heywood Health Care LLP / Rochdale West LLP/Bury CCG
- North Manchester Clinical Commissioning Group
- South Manchester CCG
- Tameside and Glossop CCG
- Stockport PCT/Stockport Managed Care
- Wigan Borough CCG

The Advancing Quality Alliance (AQuA) are co-partners in the programme, providing an AQuA affiliate to support each of the PCT clusters. The affiliate for Greater Manchester is Liz Twelves.

End of life care is priority in the programme and opportunities for collaborative working to support commissioning should be explored.

3.4 Transition Alliance and AQuA

The Transition Alliance has developed the NHS and Social Integration Project, which is sponsored by ADASS North West and delivered by AQUA. The emphasis is on organisations working in partnership across health and social care to deliver more effective and efficient services, in particular relation to older people in changing times and with significant constraints. The project has developed a number of exchange workshops to identify regional examples of good practice. Greater Manchester and Cheshire Cancer Network are supporting an event on January 25th 2012 "How integrated working can deliver better outcomes for people at the end of their lives".

3.5 Advancing Quality Alliance and Clinical Commissioning Groups Events 2012

“Do you want to make a difference to your patients who are likely to die in the next year and do you know who they are evidence suggests that at least 1% of your patient population is in last year of life”.

A series of four identical half day workshops co-ordinated by AQuA (Advancing Quality Alliance) and in collaboration with the end of life care teams, within the three cancer networks in the North West, are to be delivered in February and March 2012. The workshops are set in the context of *Finding the 1% campaign* (<http://www.dyingmatters.org/gp>) and the *RCCPs/RCN End of Life Care Patient's Charter*. The purpose of these workshops is to provide resources and thought provoking sessions that will give solutions to delivering high quality end of life care within the Clinical Commissioning Groups.

4.0. Recommendations

The North West end of life care clinical networks have maintained a relentless focus on promoting a variety of end of life care initiatives which go some way to delivering the end of life care strategy. However as can be seen from this report, there is still more work to do before we are able to deliver the full end of life care strategy. The following recommendations are therefore put forward for your consideration and to support commissioners strategic planning for end of life care.

1. Clinical Commissioning Groups need to identify an end of life care lead to Chair a locality group to develop a strategy to inform funding priorities.
2. The locality strategy should incorporate raising awareness of death and dying and support the local implementation of the national initiative '*Dying Matters*'.
3. Continued implementation of the national end of life care tools, GSF, PPC, LCP.
4. Develop a model of advance care planning across the locality.
5. Implement and monitor electronic palliative care system across the locality.
6. 24hr support for patients and families including access to district nursing and specialist palliative care, should be in place and compliant with the Improving Outcomes Guidance and Peer Review measures.
7. Implementation of a regional DNACPR policy.
8. The locality strategy should include a plan for training and education of the health and social care workforce.
9. Organisations delivering end of life care should meet the NICE Quality Standards.

5.0. Summary and next steps

This End of Life Baseline Report has been developed for the Greater Manchester PCT Cluster and Clinical Commissioning Groups as a resource to support commissioners further develop their strategic priorities and plans for delivering high quality end of life care for the patients, families and carers across the conurbation, by setting out why tackling end of life is important, outlining the critical success factors to deliver high quality end of life care and how to achieve them, data and evidence underpinning success and identifying areas for improvement.

Chief Executives are asked to receive this report and support the key initiatives and campaigns happening locally to drive change and improve quality and cost; and to share with key stakeholders including Clinical Commissioning Groups.

Clinical Commissioning Groups are asked to receive the recommendations in this report and using the resources available, identify the ways and means of building on the achievements to date, whilst scaling up improvement across all the key quality areas defined to deliver the end of life care strategy for Greater Manchester and support delivery of the QIPP challenge.

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<http://www.demos.co.uk/publications/dyingforchange>
10. NHS North West End of Life Clinical Pathway Group, Report 2010.
11. Barbara Gomes, Natalia Calanzani, Irene J Higginson, *Local Preferences and place of death in regions within England 2010*, August 2011.
12. Information Standards Board for Health and Social Care, Advance Notification – new Standard, End of Life Care Coordination, 1 August 2011. <http://www.isb.nhs.uk/documents/isb-1580-end-of-life-care/amd-11-2011/1580112011an.pdf>
13. National Institute for Health and Clinical Excellence, *Quality Standard for end of life care for adults*, November 2011. <http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp>
14. Greater Manchester Cheshire Cancer Network End of Life Care Performance Report 2010

Appendix 1.

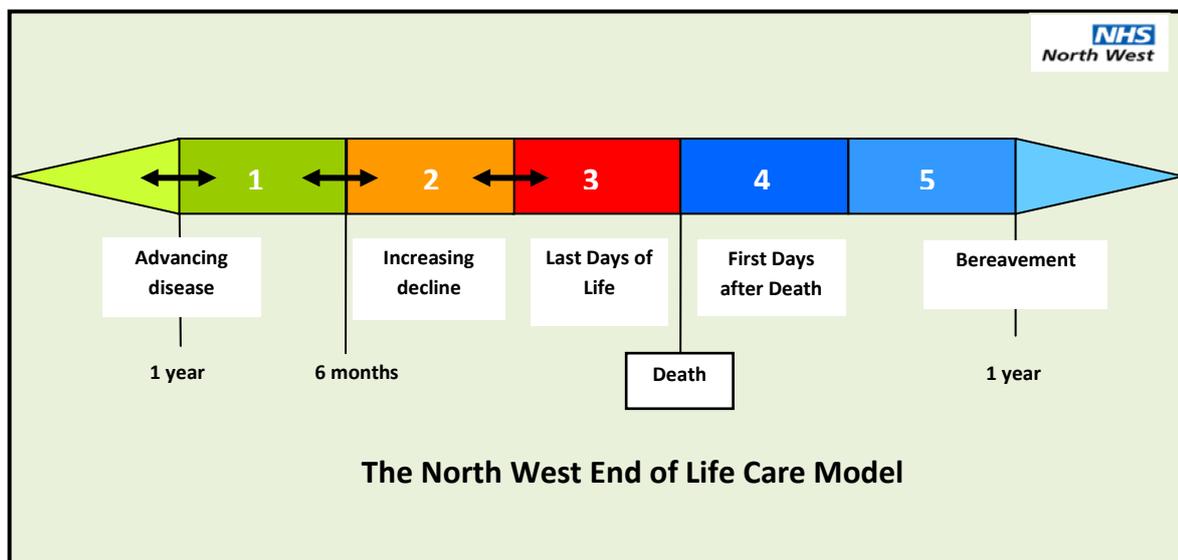
Resources

- National end of life intelligence network – <http://www.endoflifecare-intelligence.org.uk>
- National end of life care programme <http://www.endoflifecareforadults.nhs.uk/>
- Find your 1% Campaign – helping GP’s deliver quality end of life care – <http://www.dyingmatters.org>
- Dying matters – a broad based national coalition led by the National Council for Palliative Care, which aims to make living and dying well the norm through changing knowledge, attitudes and behaviours towards dying, death and bereavement. <http://www.dyingmatters.org>
- Local preferences and place of death in regions within England 2010, a report commissioned by the National End of Life Care Intelligence Network and published by Cicely Saunders International, August 2011. <http://cicelysaundersfoundation.org>
Report can also be found on the National End of Life Care Intelligence Network website <http://www.endoflifecare-intelligence.org.uk>
- The Kings Fund, Delivering better care at end of life, the next steps, January 2010. <http://www.kingsfund.org.uk>
- The Kings Fund, Implementing the End of Life Care Strategy, lessons from good practice, October 2010. <http://www.kingsfund.org.uk>
- The Kings Fund, Transforming our healthcare system: Ten priorities for commissioners, May 2011. <http://www.kingsfund.org.uk>
- The Kings Fund, Issues facing commissioners of end-of-life care, September 2011. <http://www.kingsfund.org.uk>
- VOICES (Views of Informal Carers – Evaluation of Services), a questionnaire of the experiences of care provided at the end of life. University of Southampton. <http://www.southampton.ac.uk/voices/>
- The route to success in care homes resource package; developed to support care homes to deliver high quality end of life care. <http://endoflifecareforadults.nhs.uk/care-settings/carehomes/route-to-success-in-care-homes-package>
- End of Life Care Quality Assessment (ELCQuA) Tool – to help commissioners and providers of end of life care monitor the quality of services. <http://endoflifecare-intelligence.org.uk/resources/tools/elcqua.aspx>
- The Gold Standards Framework – improving the care for all people near the end of life provided by frontline generalist staff in any setting. <http://goldstandardsframework.org.uk>
- Liverpool Care Pathway for the Dying Patient (LCP) – an integrated care pathway used at the bedside to drive up sustained quality of the dying in the last hours and days of life. <http://mcpil.org.uk/liverpool-care-pathway/index.htm>
- Skills for Health Functional Analysis – identifies the community workforce skills required to ensure that an individual in their last year of life receives quality care. http://endoflifecareintelligence.org.uk/end_of_life_care_models/skills_for_health.aspx
- End of life care innovation projects funded through Regional Innovation Fund <http://www.advancingqualityalliance.nhs.uk/innovation/casestudies/>

Appendix 2.

The North West End of Life Care Model

The model of delivery advocated by the clinical pathway group uses a whole systems approach for all adults with a life limiting disease regardless of age and setting, moving from recognition of need for end of life care, to care after death. In order to apply the model, staff across organisations are required to understand the needs and experiences of people and their carers. The pathway model identifies five key phases:-



The model comprises five phases as described below with some examples of practice highlighted

1. **Advancing disease** – timeframe 1 year or more. Example of practice required -the person is placed on a supportive care register in General Practitioner (GP) practice/care home. The person is discussed at monthly multidisciplinary practice/care home meetings (GSF).
2. **Increasing decline** – timeframe 6 months [approximate]. Example of practice required -. DS1500 eligibility review of benefits, Preferred Priorities for Care (PPC) noted, Advance Care Plan (ACP) in place and trigger for continuing healthcare funding assessment.
3. **Last days of life** – timeframe last few days. Examples of practice required - primary care team/care home inform community and out of hours services about the person who should be seen by a doctor. End of life drugs prescribed and obtained, and Liverpool Care Pathway (LCP) implemented
4. **First days after death** – timeframe first few days. Examples of practice required include prompt verification and certification of death, relatives being given information on what to do after a death (including D49 leaflet), how to register the death and how to contact funeral directors
5. **Bereavement** – timeframe 1 year or more. Examples of practice required include access to appropriate support and bereavement services if required

Appendix 3. Hospital deaths by disease group – all NW PCT clusters.

Hospital Deaths (by Disease Group)

Deaths at Usual Place of Residence

- **Operating Framework Indicator : SQU02 % Deaths at Home (inc Care Homes)**
- To improve end of life care by allowing more patients the choice of dying at home
- Percentage of deaths in usual place of residence (with usual place of residence being defined as: home, care homes (NHS and non-NHS) and religious establishments.
- Good performance is represented by an increasing proportion of deaths occurring in usual place of residence. The proportion of patients supported to remain in the usual place of residence until the end of their life should show an increase in 2011/12 over the baseline at both PCT and SHA level
- Baseline year : 2009
- Data Source : ONS
- Monitoring Frequency : Quarterly on a rolling 12 month basis

Organisation	Total Hospital Deaths CHD	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
Cheshire	286	135	54	97
Cumbria	126	60	23	43
Greater Manchester	523	243	91	189
Lancashire	268	136	39	93
Merseyside	275	124	62	89
NHS North West	1,478	698	269	511

Organisation	Total Hospital Deaths COPD	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
Cheshire	161	69	30	62
Cumbria	81	28	14	39
Greater Manchester	394	143	83	168
Lancashire	209	95	35	79
Merseyside	178	70	38	70
NHS North West	1,023	405	200	418

Organisation	Total Hospital Deaths Dementia	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
NHS North West	257	35	16	206

Organisation	Total Hospital Deaths Heart Failure	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
Cheshire	305	98	38	169
Cumbria	137	40	19	78
Greater Manchester	603	161	108	334
Lancashire	346	96	55	195
Merseyside	162	42	31	89
NHS North West	1,553	437	251	865

Organisation	Total Hospital Deaths Stroke	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
Cheshire	522	166	89	267
Cumbria	241	80	42	119
Greater Manchester	1,091	322	172	597
Lancashire	635	187	121	327
Merseyside	439	137	88	214
NHS North West	2,928	892	512	1,524

Organisation	Total Hospital Deaths Other	Total Hospital Deaths Within 3 days of admission	Total Hospital Deaths Within 4-7 days of admission	Total Hospital Deaths Over 8 days of admission
Cheshire	4,623	1,431	793	2,399
Cumbria	1,881	581	345	955
Greater Manchester	10,103	2,932	1,772	5,399
Lancashire	5,593	1,743	1,033	2,817
Merseyside	4,469	1,373	806	2,290
NHS North West	26,669	8,060	4,749	13,860

Data source: Hospital Episode Statistics 2009/10 and ONS

Appendix 4.

Deaths at usual place of residence by disease group – all NW PCT clusters.

Deaths at Usual Place of Residence by disease group						
Deaths at Usual Place of Residence	<ul style="list-style-type: none"> • Operating Framework Indicator : SQU02 % Deaths at Home (inc Care Homes) • To improve end of life care by allowing more patients the choice of dying at home • Percentage of deaths in usual place of residence (with usual place of residence being defined as: home, care homes (NHS and non-NHS) and religious establishments. • Good performance is represented by an increasing proportion of deaths occurring in usual place of residence. The proportion of patients supported to remain in the usual place of residence until the end of their life should show an increase in 2011/12 over the baseline at both PCT and SHA level • Baseline year : 2009 • Data Source : ONS • Monitoring Frequency : Quarterly on a rolling 12 month basis 					
	Organisation	Total Deaths - CHD Males aged 20-39	Total Deaths - CHD Males aged 40-59	Total Deaths - CHD Males aged 60-79	Total Deaths - CHD Males aged 80-84	Total Deaths - CHD Males aged 85+
	Cheshire	4	102	409	185	270
	Cumbria	3	46	213	85	131
	Greater Manchester	13	297	1,051	357	451
Lancashire	9	152	583	228	307	
Merseyside	7	129	489	162	168	
NHS North West	36	726	2,745	1,017	1327	
Organisation	Total Deaths - CHD Females aged 20-39	Total Deaths - CHD Females aged 40-59	Total Deaths - CHD Females aged 60-79	Total Deaths - CHD Females aged 80-84	Total Deaths - CHD Females aged 85+	
Cheshire	0	21	215	140	401	
Cumbria	1	12	111	60	173	
Greater Manchester	1	81	473	305	677	
Lancashire	1	43	292	186	459	
Merseyside	1	41	250	146	243	
NHS North West	4	198	1,341	837	1953	
Organisation	Total Deaths - CHD Persons aged 20-39	Total Deaths - CHD Persons aged 40-59	Total Deaths - CHD Persons aged 60-79	Total Deaths - CHD Persons aged 80-84	Total Deaths - CHD Persons aged 85+	
Cheshire	4	123	624	325	671	
Cumbria	4	58	324	145	304	
Greater Manchester	14	378	1,524	662	1,128	
Lancashire	10	195	875	414	766	
Merseyside	8	170	739	308	411	
NHS North West	40	924	4,086	1,854	3,280	

Appendix 5.

Place of death indicator – 2008 Q3 – 2009 Q2 and 2009 Q3 – 2010 Q2 – all NW PCT clusters.

Place of Death Indicator - 2008 Q3 - 2009 Q2 and 2009 Q3 - 2010 Q2		
 <p>Deaths at Usual Place of Residence</p>	<ul style="list-style-type: none"> • Operating Framework Indicator : SQU02 % Deaths at Home (inc Care Homes) • To improve end of life care by allowing more patients the choice of dying at home • Percentage of deaths in usual place of residence (with usual place of residence being defined as: home, care homes (NHS and non-NHS) and religious establishments. • Good performance is represented by an increasing proportion of deaths occurring in usual place of residence. The proportion of patients supported to remain in the usual place of residence until the end of their life should show an increase in 2011/12 over the baseline at both PCT and SHA level • Baseline year : 2009 • Data Source : ONS • Monitoring Frequency : Quarterly on a rolling 12 month basis 	
Organisation	2008 Q3 - 2009 Q2 % Deaths at home	2009 Q3 - 2010 Q2 % Deaths at home
Ashton, Leigh and Wigan	33.50	33.49
Blackburn with Darwen	38.76	36.80
Blackpool	31.85	37.35
Bolton	34.44	35.74
Bury	36.94	37.66
Central and Eastern Cheshire	36.86	38.15
Central Lancashire	36.51	36.89
Cumbria	39.96	43.12
East Lancashire	39.55	40.41
Halton and St Helens	37.78	39.59
Heywood, Middleton and Rochdale	35.15	36.98
Knowsley	37.26	38.03
Liverpool	33.86	35.45
Manchester	30.87	32.65
North Lancashire	36.90	38.27
Oldham	36.90	32.88
Salford	31.39	31.51
Sefton	39.45	39.87
Stockport	36.86	34.95
Tameside and Glossop	30.00	29.99
Trafford	31.61	31.91
Warrington	37.18	40.90
Western Cheshire	37.70	38.74
Wirral	36.24	38.50
NHS North West	35.79	37.03

Data source: ONS

Appendix 6.

Glossary

Preferred Priorities for Care (PPC)

The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life National End of Life Programme (2007)

The PPC is intended to be a patient-held record that will follow the patient through their path of care into the variety of differing health and social care settings.

<http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

Gold Standards Framework (GSF)

The aim of the Gold Standards Framework (GSF) is to develop a practice-based system to improve the organisation and quality of care for patients in the last stages of life in the community, so that more live and die well in their preferred place of choice. Utilising the GSF elements, the GP holds regular multi professional meetings to discuss the care of the end of life care patients in his/her practice. This ensures clear communication and collaborative care that benefits the patients. The GP is awarded Quality Outcomes Framework points for this practice (QOF)

<http://www.goldstandardsframework.nhs.uk/>

Liverpool Care Pathway for the Dying Patient (LCP)

The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life by clinicians assessing the patient against evidence based elements of care e.g. symptom management. The pathway follows the approach of ensuring best practice for the patient and includes clear goals of care, communication and co-ordination and monitoring and evaluating and identification of appropriate resources to deliver the care.

<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

Advance Care Planning

Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progress. <http://www.endoflifecareforadults.nhs.uk/>

Electronic Palliative Care Co-ordinating Systems

The concept of an electronic, palliative care, coordination system (EPCCS), also known as a 'locality register', has been considered a potentially useful tool for improving end of life care in England for several years. The system is effectively a register that holds key information about individuals nearing the end of life, thus helping the multidisciplinary team to coordinate care effectively. Information includes details of diagnosis and people's preferences for end-of-life care (Table 1). Individual records are accessible by a wide range of professionals and agencies involved in the patient's care throughout the 24-hour period.

<http://endoflifejournal.stchristophers.org.uk/national-end-of-life-care-programme/the-development-of-an-electronic-palliative-care-coordination-system>