End of Life Care Strategy (Adults) 2014/15 – 2016/17

Chorley, South Ribble and Greater Preston

Integrated Health and Social Care Economy

NHS
Chorley and South Ribble
Clinical Commissioning Group

Lancashire
County
Council

NHS
Greater Preston
Clinical Commissioning Group

St Catherine's
hospice care

Lancashire Teaching Hospitals NHS
NHS Foundation Trust

Lancashire Care NHS
NHS Foundation Trust

North West Ambulance Service NHS
NHS Trust

Contents page

Executive summary

Across Greater Preston and Chorley South Ribble CCG end-of-life care is provided in a variety of organisational settings by a range of health and social care professionals. This includes as providers Lancashire Teaching Hospitals, Lancashire Care Foundation Trust, St Catherine's Hospice and Lancashire County Council, and as commissioners Greater Preston CCG and Chorley and South Ribble CCG.

All our organisations recognise that if service improvement for end of life should be addressed it requires a whole-systems approach; in which attention is given to the entire pathway of care to ensure that high-quality care is achieved irrespective of the location.

In developing our strategy we have taken a whole-systems approach to end-of-life care as there are benefits from t h e availability of a range of services across the patients care, such as facilitation of discharge from the acute setting, rapid response services during periods out of hospital, and centralised co-ordination of care provision in the community.

Across the Health economy all partners have recognised the importance of communication and open discussion between health and social care staff, and for people approaching the end of their lives and their carers to ensure that those providing care are aware of the needs and preferences of each individual.

Executive summary (cont.)

The aim of developing our End of Life Care Strategy is to ensure our population has access to high-quality care for all over 18 year old people approaching the end of life, irrespective of gender, ethnicity, religious belief, sexual orientation, diagnosis or socio-economic status. This also encompasses vulnerable groups e.g. homeless people, and people residing in prisons and care homes.

The Health Economy aims to provide a well-informed population with co-ordinated care that identifies and respects their preferences and wishes. The care will be delivered by an appropriate range and level of services whose staff have the required knowledge and skills to deliver high quality care.

This will be achieved by:

- Increasing public awareness and discussion about death and dying.
- Agreeing the model and level of services required.
- Promoting and supporting the consistent use of nationally recommended tools across the health economy.
- Co-coordinating care through improved IT systems.
- Identifying education and training needs and supporting delivery of education and training for Health and Social care staff.
- On-going engagement with patients, families, carers and other stakeholders in service development and feedback.
- Regular monitoring of agreed outcomes and data so that it can be demonstrated how the strategy has impacted people approaching the End of Life their families and carers.

Introduction

This strategy outlines how the health economy across Greater Preston and Chorley & South Ribble, working with end of life care (EoLC) working group stakeholders, propose to improve EoLC for all patients through the seamless integration of services working towards standards of good practice over the next three years (2014-2017).

It is intended that the strategy be considered as a framework, within which detailed action plans can subsequently be produced to deliver the overarching principles stated within the strategy. It is important to engage the community further in the planning of this strategy to ensure that the views and opinions of local residents, patients and carers shape its development.

Given the breadth of patient conditions in which end of life care is relevant it is recognised that this strategy will need to be linked into and placed in the context of other transformation programmes, where work is already underway including Urgent, Elective and Primary Care.

Following the agreement of this strategy, further work will be undertaken to develop a health and social care cross-economy implementation plan. This will be underpinned by a health needs assessment, the development of a service model for end of life care and will be informed by a set of commissioning and provider intentions. The implementation plan for End of Life Care will be practical and relevant to Greater Preston and Chorley & South Ribble adult residents. It is the basis upon which various initiatives will be undertaken by the end of life working group for improving End of Life Care over the next three years.

Implementation of this strategy will raise the profile and importance of preference in death and dying across all care settings and disease groups by opening up discussions on preference for end of life care considering settings, care, treatment, communication and support for those bereaved.

Introduction (cont.)

For the purposes of this strategy patients are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions (e.g. advanced cancer, heart failure, COPD, Stroke, chronic neurological conditions, end stage organ failure and dementia)
- general frailty and co-existing 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.

And also includes:

- Care given in all settings (e.g. home, acute hospital, residential home/nursing home, hospice, community hospital and other institutions)
- Patients, carers and family members (including bereavement care given up to and after death)

Our vision for end of life services

We will commission and provide end of life services that are delivered collaboratively providing high quality effective integrated services based on the patient's needs and preferences. We aim to achieve the death that the patient wishes.

Challenges

Nationally the number of deaths each year in the United Kingdom is expected to rise by 17 per cent between 2012 and 2030. In addition, the average age at death is predicted to increase, and those dying are likely to have increasingly complex co-morbidities (Gomes and Higginson 2008). These projections indicate that the commissioning and delivery of high-quality, equitable end of life care is likely to pose a considerable challenge in the future.

The delivery of end of life care has historically suffered from underinvestment. Furthermore, death and dying are seen as 'the last taboos', and the reluctance to talk about these issues increases the likelihood of patient preferences not being discussed or met.

Our vision for end of life services (cont.)

Challenges (cont.)

The issue of identifying preferences and unnecessary hospital admissions has been one of the main drivers for the development of an end of life strategy locally. Research suggests that two thirds of people would prefer to die at home, while in reality only about one third of individuals actually do (Higginson 2003). This is also reflected locally by our current data.

Our Joint Strategic Needs Assessment demonstrates that both Greater Preston CCG and Chorley & South Ribble CCG have an increasing ageing population and increased prevalence of long term conditions.

We aim to ensure our services enable patients to have their preference of care when approaching their end of life and are able to be supported to die in their preferred place of care. We also recognise a need to reform current patterns of care, such as unnecessary hospital admissions at the end of life, and this is also a key driver for improving the quality of the end of life care offered whilst ensuring the best use of financial resources.

Our vision for end of life services (cont.)

What our strategy aims to deliver:

- The best possible care for patients at the end of their lives.
- Improvements in equity of access to services.
- Appropriate support services for patients approaching end of life Services.
- Provision of information on all options of end of life care for patients who are approaching their end of life.
- Improvements in co-ordination of care among stakeholders.
- A culture which enables people to expect compassion, kindness and a skilled application of knowledge and that enables people to be in their preferred place of care when they die and for it to be seen as a successful care outcome.
- Resources sufficient to provide care of excellent quality and which support patients in their preferred place of death were possible.
- The development and improvement of both palliative and specialist palliative care across the health economy able to deal with patients with complex needs and to support those generalists caring for patients with less complex needs.
- Care homes and agencies supported to provide excellent generalist end of life care for all those with terminal conditions whether malignant or otherwise.
- End of life care education programmes for Health and Social Care staff.
- Bereavement support for families and carers.

National policy context

In July 2008 the Department of Health published the End of Life Care Strategy for England and Wales launching a comprehensive programme to transform the care given to people approaching the end of life, their families and their carers. However, in April 2013 the responsibility for the End of Life Care Strategy moved from the Department of Health to NHS England.

There is a focus on the Electronic Palliative Care Co-ordination Systems (EPaCCS), integrated care and improving care for conditions such as dementia, helping to deliver on the Prime Minister's Dementia Challenge. End of life care will also have relevance to the other domains from the NHS Outcome Framework. The other domains are preventing people from dying prematurely, enhancing quality of life for people with long-term conditions, helping people to recover from episodes of ill health or following injury, ensuring that people have a positive experience of care and treating and caring for people in a safe environment; and protecting them from avoidable harm.

Key national priorities are

- A national aim is to have deaths in usual place of residence increased to 47% by 2015 (in England) from the current 44.51%.
- To achieve a 70% roll out of EPaCCS by 2015.
- Increase the use of Advanced Care Plans.

National policy context (cont.)

Ministers have made a commitment to evaluate progress on end of life care to determine whether it is possible to introduce a right to choose to die at home. The focus will continue to be on supporting patients to be cared for and to die in their preferred place of care and in providing community-based services to enable this to happen. Integration of services between the statutory, voluntary and private sectors is the key to success.

On 11 November 2014, NHS England published 'Actions for End of Life Care: 2014-16' which sets out NHS England's commitment to end of life care and is one component of a wider ambition to develop a vision for end of life care beyond 2015.

In August 2011, the National Institute for Health and Care Excellence (NICE) published the Quality Standard for End of Life Care for Adults (QS13). This standard defines clinical best practice and provides specific, concise quality statements which define high-quality end of life care. This quality standard has since been revised to reflect the gradual phasing out of the Liverpool Care Pathway and ensure the quality standard remains current.

National policy context (cont.)

The National Audit Office (NAO) carried out an End of Life study in Sheffield in November 2008. The findings highlighted that 40% of those who died in hospital had no medical need to be there, and could have died elsewhere had the necessary support services been available. The study also estimated that if those patients with no need to be in hospital had been discharged, it could have released approximately £4.5m per annum for commissioners to invest in community-based end of life care services.

In the 2013 Voices Survey the overall quality of care has not changed significantly from the previous years. Quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home. For those dying at home, the quality of coordination of care was rated significantly lower in 2013 compared to 2012. The dignity and respect for patients shown by hospital nurses and hospice nurses has increased between 2011 and 2013. Pain is relieved most effectively in the hospice setting (62%) and least effectively at home (18%). Only half of people (50%) who express a preference to die at home actually die at home.

EPACCs

EPACCS (Electronic Palliative Care Co-ordination Systems) is an electronic system that provides a palliative and end of life specific record sharing for clinicians. This system allows all clinicians involved in a patient's end of life care to view and edit a master copy of the patient records. This will provide a joined up health economy wide approach to record sharing and improve quality of care for patients approaching end of life.

This will require all end of life providers to have the required software to access the records. The Software has currently been installed onto all GP practices computer systems. The national ambition for end of life care is to achieve a 70% roll out of EPaCCs by mid 2015.

National policy context (cont.)

Gold Standards Framework (GSF)

The GSF was initially developed for use in primary care settings so that people approaching the end of life can be identified, their care needs assessed and a plan of care with relevant agencies put into place. In order to meet the Quality Outcome Framework (QOF) all GPs are required to retain a list of all patients with a palliative diagnosis. GSF is concerned with improving the quality, coordination and organisation of care in primary care, care homes and acute hospitals to enable people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.

Nationally the Dying Matters Coalition promote the “Find Your 1%” campaign. Dying Matters are working with Macmillan and the Royal College of General Practitioners to ensure they provide clinicians with the information and resources they need to support a good death. This campaign focuses on the one percent of a GP’s patients that will die in any given year. The Find Your 1% campaign aims to help GPs identify those patients who have a year or less to live.

Locally the End of Life Health economy are supporting this campaign to increase the number of patients on GP registers through the transform educational training programme and the introduction of EPaCCs.

National policy context (cont.)

Advance care planning

Advance Care Planning is a voluntary process of discussion and review with the aim of helping someone who has the capacity to indicate what their preferences and wishes are for future care.

If the individual wishes, they can record preference about their care and treatment and an Advance Decision to Refuse Treatment (ADRT) in specific circumstances. These preferences can then be referred to by those responsible for care and treatment if, as the illness progresses, the individual loses capacity to make decisions for themselves.

Advance planning should be robustly discussed, documented and shared with other health professionals involved in the patient's care. Families, carers and professionals involved in the patient's care should be aware of the Advance Care Plan and be clear on the actions which should be undertaken when the patient's health significantly deteriorates. This includes the use of medication, resuscitation and ambulance call-outs.

Emerging policy issues

The Liverpool Care Pathway (LCP) was developed by Royal Liverpool University Hospital and Liverpool's Marie Curie Hospice in the late 1990s for the care of terminally ill cancer patients; it was then extended to include all patients deemed to be dying. While initial reception was positive, it was heavily criticised in the media in 2009 and 2012.

A national review of the LCP was conducted by the Leadership Alliance headed by Baroness Julia Neuberger. The review was established after concerns were raised by patients, families, carers and a number of clinicians. The findings of the review highlighted that in the right hands and when operated by well-trained, well-resourced and sensitive clinical teams the LCP did help patients have a dignified and pain-free death, however, findings also outlined too many cases of poor practice, poor quality care of the individual, with families and carers not being properly engaged in the patient's care. Because of these failings, the review recommended that the LCP should be phased out by the 14th July 2014.

Following the Neuberger review the Leadership Alliance released a document titled 'One Chance to Get it right' in June 2014. The document details 5 key priorities of care for palliative and end of life patients:

- The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.
- Sensitive communication takes place between staff and the person who is dying and those important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care.
- The people important to the dying person are listened to and their needs are respected.
- Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

The health economy across Chorley, South Ribble and Greater Preston are working together to develop a locally joined up approach to EoLC planning to ensure consistency of care across all partners.

Emerging policy issues (cont.)

Difficult Conversations

Very few adults, including older people, have discussed their own preferences for care at the end of their life. Often patients have not had these discussions with a close relative or friend. Adding to this clinical and care staff have not received training in how to have such discussions. In the absence of open discussions it is difficult to understand a patient's needs and preferences for care and to plan accordingly.

The wishes of people approaching the end of their life are not always conveyed to those who need to know. Such data should ideally be captured in the Summary Care Record; but until it is fully operational, the department through the national end of life care programme should support commissioners to develop protocols to help capture, document, and share accurate patient information on preferences. This information should be regularly updated and shared with all providers across the health, social care, independent and voluntary sectors who influence decisions concerning where and how patients receive care.

Coordination of Care

Often at the end of life, a patient will need the care of multiple services and professionals. It is often necessary for several organisations and agencies to be involved with the care of an individual patient, with the patient often moving locations (home, hospital, care home, hospice etc.) Due to this, there is significant risk that coordination of a patient's care can be poor.

A lack of coordination between services or a single point of contact can lead to frustration for patients and carers. Commissioners need to commission effective coordination of end of life care services through a single point of contact for patients and carers, including access to advice and carers assessments.

Emerging policy issues (cont.)

Access to services at whatever time of day (or night)

People who are at, or approaching, the end of life need access to care and support 24 hours a day, 7 days a week. Often services in the community are unable to respond to these needs, resulting in an increase in emergency attendances and admissions to hospital as opposed to patients being cared for in their usual place of residence.

Complex Care

It must be recognised that patients at the end of life may have additional complex physical, learning or mental disabilities which may not be identified, resulting in inadequate care.

As a result of all the challenges identified above many people experience unnecessary physical, psychological and spiritual suffering, which prevents many people from living out their final days in a preferred place of care and often has a negative impact on how family and friends cope during the bereavement phase.

Support for Families/Carers and Bereavement Services

Families and carers are an integral part of end of life care and are fundamental to the successful delivery of care. Support for family and carers throughout a person's illness and into bereavement is often inadequate. This can impact adversely on the health and wellbeing of carers and make it difficult for them to provide care.

Training and Support for Staff

The training and support of all staff that care for patients at the end of life is paramount to the success of the care planning.

Scope of strategy

Services will need to be commissioned across a number of different settings; patient's own home, care homes, sheltered/extra care housing, hospices or hospitals. On some occasions they will also be needed in other locations such as hostels for the homeless and independent living homes for people with learning disabilities and mental health problems.

Principal objectives of this strategy are to

- Increase public awareness and discussion of death and dying: This will make it easier for individuals to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality.
- Ensure that all people are treated with dignity and respect as they approach the end of their lives.
- Ensure that pain and suffering amongst people approaching the end of life is kept to an absolute minimum.
- Ensure that all those approaching the end of life have access to physical, psychological, social and spiritual care.
- Ensure that people's needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon wherever possible.
- Ensure that the many services people need are well coordinated, so that patients receive seamless care.
- Ensure that high quality care is provided at the end of life, and after death.
- Ensure that carers are appropriately supported both during a patient's life and after bereavement.
- Ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care.
- Ensure that services are effective and efficient.

Scope of strategy (cont.)

Dementia and End of Life Care

One in three people over the age of 65 will die with some form of dementia (Brayne et al, 2006). As the population ages and more people develop dementia, end of life issues will become increasingly important, not only in dementia care, but for society as a whole.

Dementia is the third most common underlying cause of death for women in England and Wales, behind heart disease and stroke. It is the seventh most common cause of death in men.

In 2012, the Prime Minister's Challenge on Dementia was published. The report built on the National Dementia Strategy published in 2009 and set out a three year programme of improvements in dementia care and also acknowledged the importance of improving end of life care for people with dementia.

Currently, many of the systems for end of life care are designed around people with cancer, rather than people with dementia. People with dementia may not be referred for specialist end of life care (such as at a hospice), and specialists in end of life care are more used to dealing with conditions with a steep period of decline, such as cancer, rather than the more uncertain prognosis of dementia. This may be, in part, because dementia is not generally recognised as a terminal condition.

The development of advance care plans has been identified as a national and local priority. It is particularly important to have discussions with people with dementia and their carers about end of life wishes as early as possible after diagnosis. Diminishing capacity becomes a particular problem in end of life care for people with dementia. Having end of life discussions at an early stage enables people with dementia to make their preferred place of death known, and also allows enduring power of attorney to be set up in advance of it being required, rather than at a time of crisis.

Advance care plans can be particularly important in the end stages of dementia when it comes to decisions about withdrawing treatment. Withholding or withdrawing treatment is one of the most ethically complex and emotionally challenging aspects of end of life care. It is made particularly challenging in dementia where a person has lost capacity and may not have left instructions about their wishes.

Scope of strategy (cont.)

Dementia and End of Life Care (cont.)

In October 2012, the Alzheimer's Society published a report on end of life care for people with dementia, (My life until the end, dying well with dementia). In undertaking research for the report, the Society heard reports of some people with dementia being left in pain, without something to drink or unwashed for periods of time. This echoes the findings of the Ombudsman (Health Service Ombudsman, 2011), the Commission on Improving Dignity in Care (Commission on Dignity in Care for Older People, 2012) and the Royal College of Psychiatrist's hospital audit (Royal College of Psychiatrists, 2011) and the Neurburger review into the Liverpool Care pathway (2013).

Research has also suggested that the emotional and spiritual needs of people with dementia are disproportionately neglected (Sampson et al, 2006).

The report identified a number of areas for improvement:

- Greater public awareness and support for people with dementia to plan for their future care using legal provisions and in a more informal way.
- All people with dementia should be able to come to the end of their lives with dignity and free from pain, with staff training and other systems geared to support this even when communication has diminished.
- Significant, co-ordinated and holistic support for the person with dementia and their carers, regardless of the setting which they are in, which includes provision for emotional and spiritual support if required.

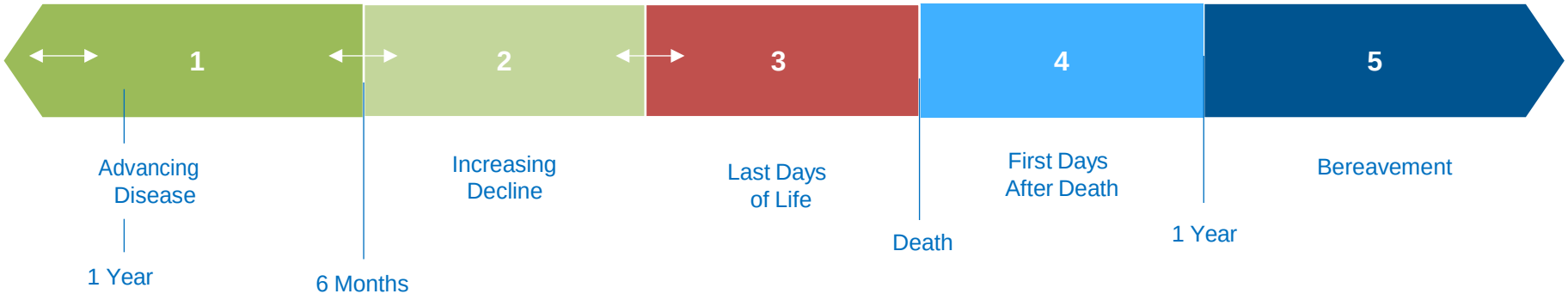
Learning Disabilities

It is recognised that people with learning disabilities (LD) and their families are likely to require specialist and additional support in end of life care due to increased complexities in co-morbidities, communication difficulties and inequality in accessing health services.

Scope of strategy (cont.)

North West Model

The North West End of Life Care Model has been produced to provide a story of a patient's health from diagnosis of a life-limiting illness to one year post bereavement as can be seen with this model. The model comprises five phases and outlines some examples of practice. Locally this model will be promoted through education and training as a model to support people to live and die well in their place of preference across the health economy.



Source: Cumbria and Lancashire End of Life Care network

Scope of strategy (cont.)

North West Model (cont.)

1. Advancing disease	Timeframe: 1 year or more. 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, care coordinators contact details given to patient and or family/carer. Advanced care planning discussed and offered. Communication with relatives/ carers needs assed and addressed.
2. Increasing decline	Timeframe: 6 months [approximate]. Examples 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. DNACPR status considered documented and communicated. Review the ACP. Undertake CHC screening.
3. Last days of life	Timeframe: last few days. Examples of 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.
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. Provide details of bereavement services to families and carers. Notify all social and healthcare professionals to enable prompt removal of equipment.
5. Bereavement	Timeframe: 1 year or more. Examples of practice required include access to appropriate support and bereavement services if required.

Current service provision

Across Chorley, South Ribble and Greater Preston many stakeholders will have input into an end of life patient's care. Below are details of provider's roles and responsibilities.

Primary Care

General Practitioners are the lead clinician in an end of life patient's care while they remain in the community. The care of an end of life patient is very individual to the specific requirements of that patient, their condition and their social situation. The GP will consider all these factors and ensure that all aspects of a dying patient's needs are met. GPs will continually assess and review the patient's needs and advise what is required to meet them. GPs provide continuity of care for patients, by often being the first port of call for patients, families and their carers as the patient's condition changes or deteriorates. GPs provide end of life patients with the individual care that they require to meet their changing and often complex needs.

To facilitate more people dying in their preferred place of care, the biggest impact will be for primary care, with the initial focus being on early identification, use of the Gold Standards Framework or equivalent and improved referral routes into specialist services in the community and increased support in order to ensure patients die in their preferred place of care.

It is recognised that, in order to support patients who are reaching the end of their life to be cared for and die in their preferred place of care, the skills, knowledge and confidence of GPs and the wider primary care teams in the community are key.

One of the key aims for Primary Care is to have the EPACCS (Electronic Palliative Care Co-ordination Systems) implemented to aid record sharing with other clinicians.

Current service provision (cont.)

Lancashire Teaching Hospitals

Lancashire Teaching Hospitals NHS Foundation Trust (LTH) provides acute and local services for a local population of around 390,000 within Preston, Chorley and South Ribble as well as providing a number of specialist services to around 1.5 million people across Lancashire and South Cumbria. LTH has 2 main hospital sites, Royal Preston Hospital (RPH) and Chorley and South Ribble District General Hospital (CDH).

The trust employs a hospital based specialist palliative care (SPC) service that covers both hospital sites. Out-of Hours advice for hospital staff is available via the 24/7 telephone advice line based at St Catherine's Hospice.

The team work closely with the local hospice and community palliative care service to ensure that patients experience a seamless service as they move between the hospital, hospice and home setting.

Community Pharmacies

To ensure the availability of palliative care drugs in Chorley & South Ribble and Greater Preston a Local Enhanced Service (LES) for Palliative Care – Stock Holding and Provision of Specialist Drugs is provided and funded for eight pharmacies across both CCGs.

The aim of this is to improve access for patients, carers and healthcare professionals to these specialist medicines when they are required, by ensuring prompt access and continuity of supply. Its aim is to reduce the number of difficulties experienced by carers and relatives in obtaining supplies of medicines needed at end of life. This LES is only provided in normal working hours.

Current service provision (cont.)

Lancashire Care NHS Foundation Trust

Lancashire Care NHS Foundation Trust (LCFT) provides health and wellbeing services for a population of around 1.5 million people across a Lancashire footprint. Community services provided by LCFT include community nursing, district nursing and community matrons , a range of therapy services including physiotherapy, occupational therapy, speech and language, dietetics, cardio-respiratory team and health and wellbeing services .

Lancashire Care Foundation Trust discharge liaison team is also based within the acute hospital to assist with seamless transitions. The Trust is also a specialist provider in inpatient and community mental health services. district nursing teams cover a 24/7/365 service

End of life care in the community is guided by the principle that care is informed by personal preference and personalised to individual needs. Community nursing teams build therapeutic relationships with patients with a palliative diagnosis and work as part of a multidisciplinary team to ensure early identification, patient involvement, ongoing communication and effective symptom management.

The community nursing teams work in partnership with other providers ensuring timely and effective integrated care. The community nursing services provide an accessible responsive service to support patients and their families to remain in their home and to avoid unnecessary hospital admission.

End of life care provided is bespoke to patient and carer needs and care planning is guided by the individual specific requirement, their condition and the social context. This is provided by staff skilled and confident in end of life care.

Current service provision (cont.)

Lancashire County Council (LCC)

Adult social care has a clear role to play when supporting people who are coming to the end of their lives, in order to develop services and support to meet this role the county council:

- Has a commitment to effective multidisciplinary working with health practitioners around assessments at end of life.
- Offers personal budgets that enable people to purchase services or employ their own staff to meet their social care needs.
- Has developed and is embedding the use of person centred tools with providers that enable people to live well and plan for their end of life.
- Is working with social care providers to develop good practice, particularly where safeguarding issues have been established.
- Developed a contract monitoring framework that assesses how well organisations support people at the end of life.
- Oncology social workers within hospital settings.
- Generic social work offer.
- Advance practitioners with responsibility around improving social work practice in this area.
- Carers support services.

Current service provision (cont.)

North West Ambulance Service (NWAS)

NWAS is often the first point of call in a deteriorating situation. It is important for the organisation to understand the most appropriate care required and to have all the relevant information available to them on arrival to the patient.

Emergency ambulances are regularly called to individuals approaching the end of life. Such calls are often triggered by deterioration in the patient's condition which is frequently complicated by an acute medical crisis. Where this crisis involves cardio-respiratory arrest, paramedics are faced with an important ethical and emotional decision as to whether or not to perform cardiopulmonary resuscitation (CPR). While guidance exists on decision making relating to the withholding of CPR, the current guidance is not explicit about the scope of the paramedic's role in this decision making process.

Out of Hours Providers (OOHs)

Chorley Medics provide out of hours primary care services to the patients of Chorley and South Ribble area from their offices in Euxton. Preston Primary Care provide out of hours primary care services to the patients of Greater Preston from their base in Royal Preston Hospital.

The end of life services that both Chorley Medics and Preston Primary Care provide are very much bespoke to the needs and requirements of the individual patient. General Practitioners will notify the out of hours providers of particular patients they feel may need input during the out of hours period. They will upload the relevant information into the computer system that then indicates to any call handler or clinician who accesses that patients records, for example a patient who has a do not resuscitate (DNR) order in place.

Current service provision (cont.)

Care Homes

Nursing and care homes play an important role in the care of older people at the end of life. Together, they provide final care for 16% of the population, rising to 30% of those aged over 85 (National End of Life Care Intelligence Network, 2010). However, it is indicated that a higher number of older people would die in a care home, if not admitted to hospital in the final stages of life (Stobbart -Rowlands & Brewster, 2010). 16% of care home residents die in hospital after an unplanned admission in their last week of life (National End of Life Intelligence Network, 2012) despite the plethora of documents, guidance, frameworks and even training programmes and resources specifically for care home staff.

The Department of Health (2008) identified inadequate training in care homes as the major cause of the failure to provide good quality end of life care (Stobbart-Rowlands & Brewster, 2008). Since then, locally, care home providers have been able to access training specifically for care home staff in relation to the end of life care. Within the Greater Preston and Chorley and South Ribble localities there are 3 care homes that are accredited with the Gold Standard Framework quality award. Staff from 42 care homes have completed the Six Steps to Success programme of education based on The Route to Success series (National End of Life Care Programme, 2010).

St Catherine's Hospice

St Catherine's Hospice is a local charity that receives a grant from both CCGs to provide services across both localities. The service provides specialist care to patients with life limiting illnesses.

It provides care for patients with malignant and non-malignant diseases such as heart failure, chronic respiratory disease, and neurological conditions. The purpose of the hospice services is to provide direct care, or support and advice, in relation to complex symptom management. This includes physical symptoms such as pain and nausea as well as psychological, spiritual, and social support. The service also provides a range of psychological and emotional support for families and carers during the course of illness and in bereavement.

Current service provision (cont.)

St Catherine's Hospice (cont.)

Services include:

- **19-Bedded Inpatient Unit** that provides the support needed for the most complex situations requiring specialist assessment and treatment. This may include acute interventions such as blood transfusions and intravenous antibiotics. The service operates 24 hours per day, 365 days per year.
- The **24-hour advice line** provides support and guidance to hospital and primary health care staff.
- The **Day Therapy Unit** operates every weekday (not bank holidays) and provides care for 15 patients each day. Interventions include medical/nursing assessments. Participants have access to a structured eight-week programme of activity to assist with the development of rebuilding of confidence to enable a greater ability to self-support.
- The Hospice also provides the **Clinical Nurse Specialist** (Community Palliative Care) service.
- A **Specialist Lymphoedema Service** provides assessment, treatment, and advice of future care to those affected by this long-term condition. The service provides **Family Support services**. Social workers provide a range of services including help with discharge planning, assessments for home care, arranging spiritual/psychological support, carers' befriending service, carers' drop-in support, whilst also acting as a resource in relation to safeguarding.
- The service provides several strands of **bereavement care** including, one-to-one counselling, informal drop-in, fixed-term therapy groups and an inclusive quarterly remembrance service of a secular style.
- **Rehabilitation service (physiotherapy and occupational therapy)** is available to patients of day therapy and inpatient services.
- The service has an **education team** that is responsible for all in-house training and has been commissioned by the NHS and Lancashire County Council to provide education e.g. end-of-life care training for social workers, Six-Steps to Success for care homes.

Current service provision (cont.)

Cancer Help (Preston) Ltd – Vine House

Core services can be accessed by self -referral and referrals through health and social care professionals, focusing on the psycho-social wellbeing of people affected by cancer and include:

- Counselling and psychotherapy services, including Mindfulness programmes.
- Bereavement support and counselling.
- Bereavement Groups for the newly bereaved and those bereaved for a longer period.
- A number of support groups are hosted at Vine House.
- Complementary therapy services.
- Breathlessness clinic for lung cancer patients.
- "Stride" – Children and Young People's Bereavement service.
- Creative therapies (art and crafting activities).
- Advice, information and signposting to other services.
- A "North of the River Ribble" base is also offered to the St Catherine's Hospice Team, enabling them to provide outreach palliative care consultant services; lympheodema services; and clinical nurse specialist services to clients nearer to home.

Current service provision (cont.)

Derian House

Medical advances in recent years have meant that children with life limiting conditions are now reaching adulthood. To enable us to support young adults a 4 bedded purpose built unit “The Lodge at Derian House” was opened in 2010 to meet the unique needs of young people aged between 16 and 26 years. It has been designed to support their transition to adult services by meeting the clinical, developmental and psychological, social, emotional and psychosocial needs of this age group, including their requirements for independence, privacy, autonomy, peer contact and recreation. The service provides:

- Short planned breaks
- Emergency stays (EOLC always a priority)
- Derian at Home
- End of life care
- Bereavement support
- Family counselling & support
- Social work advice
- Physiotherapy
- Hydrotherapy
- Play specialists

Current service provision (cont.)

Cruse Bereavement

Cruse Bereavement is a registered charity that is supplied with a grant from both CCGs to provide bereavement services across Chorley, South Ribble and Greater Preston. Cruse provides support to their clients, either with face to face (usually in the client's own home) or telephone support by training volunteers. Cruse works closely with other providers to enable signposting to other services.

Marie Curie

Are providers of specialist palliative nursing care for patients in the end stages of their life across Chorley, South Ribble and Greater Preston. Marie Curie is a registered charity that the CCGs make a financial contribution towards. The contract allows for financial alterations to be made with regard to activity. The care is planned and agreed as a combination of days, evenings and nights as appropriate to support the needs of patients and carers. Adults with all types of life limiting illness will be considered for care. The service is provided for those in whom diagnosis has shown that the advent of death is likely and not too distant and for whom treatment includes a large element of palliation.

This service consists of one to one palliative care to patients in their normal place of residence, and provides predictability of care for the patient and their carers. Care is delivered by an agreed combination of registered nurses & senior healthcare assistants with comprehensive training and current experience in end of life palliative care, who receive on-going training, education, clinical and managerial support. Care is delivered in the patient's home or other agreed location on a single patient per shift basis.

Current service provision (cont.)

Tender Nursing Care

Tender Nursing Care is a charity that receives funding from both CCGs. The service provides support to patients, carers and families who are receiving palliative care support across Chorley, South Ribble and Greater Preston. The care provided enables the respective carer to have a break from their caring role, helping to relieve the stress experienced by carers and their families. The care provided is an overnight sitting service. Referrals are primarily received from the district nursing teams.

End of Life Nursing Levels

NHS Benchmarking has outlined that end of life nursing levels should ideally be 2.58 per 100,000 population. Based on the current populations across Chorley, South Ribble and Greater Preston end of life nursing levels should be 9.96 whole time equivalent (WTE), however; staffing levels are currently 7.4 WTE, which highlights an under-resource in this area.

What should end of life care look like for patients, carers and families in Greater Preston and Chorley and South Ribble?

A patient should receive high quality end of life and palliative care from their GP, nurse, case manager, therapist, hospice, hospital, voluntary organisations and any other professional who is involved in their care.

They should be supported physically, psychologically, socially and emotionally and their own personal needs and preferences will be paramount in their care. Carers and families will also receive the help and support they need.

When approaching the end of life patients, their carers and their families should be offered the opportunity to discuss the type of care they would like to receive for the patient, and where the patient would like to be treated. Patients will also be supported to have conversations regarding where they would like to die and what is important to them and their family in the last days of their life, such as pain relief, symptom management, family issues, and spiritual guidance.

In doing so the following will be achieved:

- **Seamless end of life care for patients and their carers.** This should be based on close collaboration between health and social care services and supported by real-time patient information and a common understanding by personalised end of life care.
- **Increased awareness from patients and professionals** of end of life issues and the availability of end of life services.

Development and improvement priorities

The development of the following key priorities were shaped by the Central Lancashire Palliative and End of Life Care Strategy Group. Many of these priorities have been highlighted through previous engagement work undertaken with patients and carers and followed similar themes. The Central Lancashire Palliative and End of Life Care Strategy Group will lead on the implementation of the delivery plan over the next 3 years.

Key Priorities
Map of services
This is to review all services currently providing end of life services across Chorley, South Ribble and Greater Preston. The health economy needs an overview of end of life services to understand what all stakeholders are providing to identify gaps, avoid duplication and share best practice. The review needs to ensure that services commissioned are still fit for purpose and are sustainable for the future.
Integration
To improve integration by all stakeholders working towards working as a health economy. The aims of this work stream are to provide improved joined up working and as a result provide seamless services for our patients.
7 day access to services
To improve and increase access to service, to ensure services are available when patients require them. As a result enable patients to be treated and discharged in a timelier manner.
7 day access to specialist palliative care team
Historically, within the community and currently within Lancashire Teaching Hospital the provision for specialist palliative care nursing services has been Monday – Friday. Patients need access to services as and when needed.

Development and improvement priorities

Key Priorities (cont.)
Primary Care review of Resources
The aim of this strategy is for more patients to receive End of Life care in their preferred place of care. This will impact on primary care services. This needs to be considered and reviewed to ensure provision can meet demand and if required additional resources are in place to support GP practices, Integrated Neighbourhood Teams (INTs) and patients.
Hospice at home
The CCGs have commissioned from the hospice a twelve month ' Hospice at Home' pilot service for the community of Chorley, South Ribble and Greater Preston. This is to provide care and support to the patients of Chorley, South Ribble and Greater Preston who are approaching the last days and hours of life; the service is nurse led. With care being provided within patients homes by health Care assistants.
Care plans
Since the withdrawal of the Liverpool Care Pathway, providers do not have one personalised care plan to follow for dying patients. The health economy is working together with the national priorities for end of life care produced by the Leadership Alliance, to generate a local approach.
Development of metrics and outcome measures
Development of outcome measures are needed across Chorley South Ribble and Greater Preston to ensure the effectiveness of this strategy.

Development and improvement priorities (cont.)

Key Priorities (cont.)
Use of Advance Care Plans
All stakeholders agreed that the increased use of advanced care plans and the introduction of them as soon as a patient is identified as being in the last years of life have a positive impact on care.
Community Transform Training Programme
The Community Transform Project is to run across Greater Preston and Chorley and South Ribble CCGs. The project is to provide targeted education across the whole health economy, providing a consistent approach and messages to professionals, patients and carers. This will reflect the transforming end of life care education programme currently being undertaken in Lancashire Teaching Hospitals.

Development and improvement priorities (cont.)

Key Priorities (cont.)
Marie Curie Contract review
Marie Curie currently delivers a nursing and night sitting service. The review needs to look at the current provision and to ensure the service is sustainable for the future.
Bereavement Services review
Historically GPs have struggled to access bereavement services for carers and families who have lost loved ones and require additional therapeutic and psychological support. Currently we have a number of providers who are funded by voluntary sector grants from the CCG. The review needs to look at the current provision and to ensure the service is sustainable for the future.
Improving Technology
The use of technology needs to be utilised to ensure that services run as streamlined and integrated as possible.
Patients, families and carers engagement
All stakeholders agree that involvement of patients their families and carers improves patient experience. Patients need to be able to personalise their own end of life plan to ensure their dying wishes are met.
Inclusion of all patients
The CCGs and stakeholders want to ensure that all patients even those who can be classed as hard to reach are provided for appropriately as they approach their end of life. These include patients with dementia, long term conditions, patients who are classed as hard to reach, homeless patients, black or minority ethnic and patients with learning disabilities.

Development and improvement priorities (cont.)

Key Priorities (cont.)
Ensure more patients are dying in their preferred place of care
A large number of patients are still dying in acute settings when their preference would be to die at home/usual residence or in a community setting (i.e. hospice or nursing home). The health economy needs to work together to improve this for our patients.
Ensure that End of Life services are embedded in all services
End of life care is embedded into all services to ensure that patients are identified as approaching end of life and suitable provisions are in place.
Education and Training
The CCGs and St Catherine's Hospice developed a successful bid for Multi-Professional Education and Training (MPET) funding for 2013/14 and 2014/15. The bid is to provide a Community Transform Project across both CCG localities. The project will target education across the whole health economy including GP practices, district nurses and the integrated neighborhood teams (INTs) . The aim is to provide a consistent approach and messages to professionals, patients and carers. The project mirrors the transforming end of life care education programme being undertaken in the acute sector by Lancashire Teaching Hospitals during 2014/15. The training will be launched by having an end of life care master class, this will consist of a series of workshops and aimed at health care professionals and will provide a overview of the project to encourage practices to engage with the ongoing community transform project. The key topics are advanced care planning, gold standards framework and EPaCCs.

Next Steps

Further work will be undertaken to develop a health and social care cross-economy implementation plan. This will be underpinned by a health needs assessment, the development of a service model for end of life care and will be informed by a set of commissioning and provider intentions.

How success will be measured

Outcome measures will be used to monitor and evaluate the impact of end of life care delivery against the strategic objectives identified in this strategy. The end of life health economy will work collaboratively to ensure the implementation of this strategy and measure its impact by the below key outcomes.

Key outcomes will include:

- Aim to increase patients dying in their preferred place of care where possible in line with the national target.
- All end of life patients will be offered the opportunity of an advance care plan where appropriate.
- Operational EPaCCs system across all providers.
- Reduction in unnecessary hospital admissions for end of life patients.
- Reduction in unnecessary A&E attendances for end of life patients.
- Increase education and training in end of life care for health professionals.
- Improve outcomes in Voices Survey.

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Appendix 1 – Baseline data

Place of Death Data

Deaths in usual place of residence (which combines people's own homes and care homes) are the main marker of progress for the 2008 Department of Health End of Life Care Strategy.

This is continuing the steady rise of deaths in usual place of residence, accompanied by a drop in deaths in hospital. The DH's Fourth Annual Report published in October 2012 on the End of Life Care Strategy states nationally 42.4% of people are now dying at home or in a care home and there is a steady improvement at both national and old Strategic Health Authority levels.

In 2013 across Chorley South Ribble and Greater Preston 54% of patients died in hospital, 38% of patients died at home and the remaining 8% are classified as other but are deaths within a hospice or elsewhere. (ONS Data 2013) this data does not contain all deaths. The deaths analysed for this exclude those who died from external causes (all causes not related to disease, e.g. road traffic collision). These are excluded from the place of death analysis, as no one has any control over where those people die. Below these numbers are broken down further into each of our localities.

Appendix 1 – Baseline data

NHS Continuing Healthcare

Many patients who are approaching end of life may be assessed for NHS Continuing Healthcare Fast track which facilitates discharged or aid patients to remain in their chosen residence by providing care and support as they approach the last days and hours of their lives.

Fast track during April 2013 to March 2014 across Chorley South Ribble and Greater Preston a total of 377 patients were assessed and awarded NHS fast track status. Of these patients 271 were provided with a package of homecare, 103 patients were provided with in a nursing home placement , 1 patient was provided with a mental health placement and 2 patients received care to provide respite.

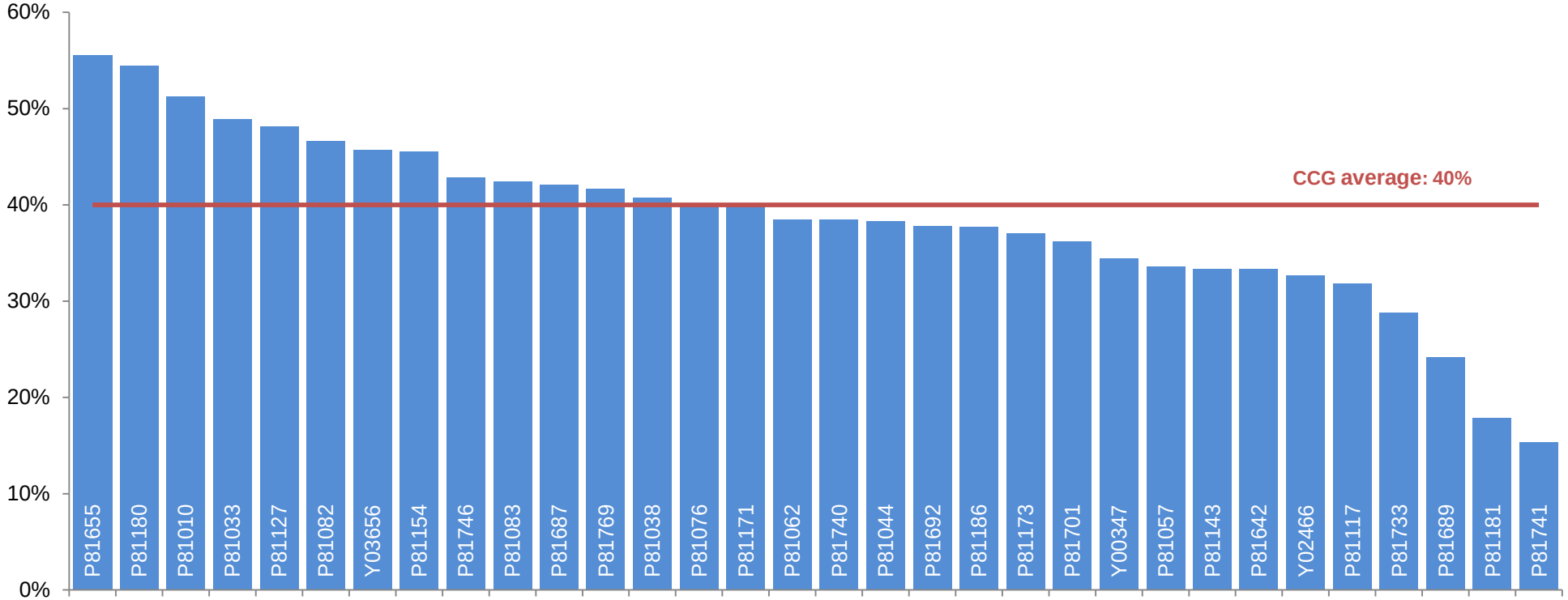
Rapid Access to Home care

Lancashire Teaching Hospitals rapid access to Home Care service during the 6 months October 2013 – March 2014 commenced 32 patients on the process. Of those patients 23 patients were discharged, with 9 being unsuccessful. Of these 10 patients were discharged on the same day, 12 patients were discharged on the next day and 1 patient was discharged within 3 days.

Appendix 2 – Delivery plan health of our population (cont.)

The below chart shows the percentage of patients dying at home for Chorley and South Ribble CCG split by each practice for 2012/13.

Percentage deaths at home by practice: Chorley & South Ribble CCG 2012-2013 (pooled data)



Appendix 2 – Delivery plan health of our population (cont.)

The below chart shows the percentage of patients dying at home for Greater Preston split by each practice during 2012/13.

Percentage deaths at home by practice: Greater Preston CCG2012-2013 (pooled data)