Northumberland Palliative and End of Life Care Strategy

Introduction

In 2019, Northumberland County Council Overview and Scrutiny Committee (OSC) tasked Northumberland Clinical Commissioning Group (NCCG) to develop a county wide strategy for palliative and end of life care for all the residents of Northumberland. The vision set out by OSC is for residents of Northumberland to receive the highest quality palliative and end of life care when needed. For the strategy to truly deliver on this vision it must be system wide, working across health and social care and the voluntary and charitable sector, encompassing care in hospitals, hospices, the community and residents own homes. Engaging with the residents of Northumberland, and ensuring hard to reach groups have equitable access to high quality palliative and end of life care.

To develop this strategy NCCG established a system wide task and finish group made up of representatives from health and social care, the voluntary sector, patient representatives and councillors from Northumberland County Council.

The task and finish group adopted a four-stage process to develop the Northumberland palliative and end of life care strategy:

- Understand how palliative and end of life care is currently delivered across Northumberland.
- Identify best practice, regional variation and gaps in service provision.
- Identify priorities across the system so that this best practice can be embedded, county-wide variation can be closed and gaps in service provision addressed.
- Describe what success looks like and how this can be measured.

Section 1 – What are we already doing

The working group are committed to understanding how palliative and end of life care across Northumberland is currently delivered. To fully understand the current palliative and end of life services, we have explored a wide range of available data sources including data from primary, community and secondary care, the national mortality index database, service mapping, engagement surveys and case studies.

In order to give a context to the wealth of information which has been collected, we have used the National Council for End of Life Ambitions which sets out the six ambitions that need to be achieved, to accomplish our vision of delivering the highest quality palliative and end of life care. Within each ambition are the building blocks required to achieve that ambition, and we have mapped current services against these building blocks, identifying best practice, regional variation as well as gaps in service provision.

Ambition 1 - Each person is seen as an individual

"I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to what's possible."

Building Blocks to Achieve this Ambition

- Effective systems are in place to reach patients who are approaching end of life.
- Patients to be given information, support and advice so they can make decisions regarding palliative and end of life care.
- Rapid access to needs based social and health care.
- Good end of life care including bereavement support.

What we have discovered?

Northumberland encompasses both extensive rural areas to the north and west of the county and urban areas in the south-east with a population density of 64 people per sq km, which is less when compared to neighbouring counties such as, County Durham (324/Km^2), Carlisle (74/km^2) and North Tyneside (2326.5/km^2).

The average life expectancy in Northumberland is approximately 79.4 years for males, which is similar to the England average of 79.6 years, whilst females can expect to live 82.7 years, compared to the England average of 83.2 years.

Alongside an ageing population, deprivation is also a key challenge. There is a difference in life expectancy of 16 years from the least deprived, to the most deprived area, with the most well off expecting to live up to 92.3 years whilst the least well off to 76.4 years.

While absolute life expectancy is a useful indicator, healthy life expectancy is arguably a more poignant indicator of health as this informs us how long we can expect to live before we are diagnosed with some form of chronic medical condition. We can see that the least deprived regions have an average healthy life expectancy of 70.4 years whilst the most deprived can expect an average of 53.0 years of healthy life, showing a stark difference of 17.4 years.

All of the population health data for all ambitions is set out in detail with the Public Health Tableau dashboard (Dashboard in process of being finalised).

What are we doing well?

All GP practices hold regular Multi-Disciplinary Team (MDT) meetings which include members of the wider community team. This gives the opportunity to identify patients with a palliative diagnosis (both cancer and non-cancer patients). The community nursing team reviews, all identify patients and where appropriate, adds those to the palliative care register with a colour coded status of red/amber/green dependent on prognosis.

Through regular MDT meetings, known patients' needs are identified and care plans are put in place, for example by application of the Gold Standards Framework. This includes use of Emergency Healthcare Plans (EHCP) to empower patients and their carers while guiding health professionals involved in their care. The EHCP is shared with all stakeholders including North East Ambulance Service (NEAS), Out of Hours GP, carers, and secondary care.

There is provision of 24/7 'hands on' care support for patients in their own home in South/Central areas of Northumberland from the Macmillan Care Support Team (MCST). This team provides care support, meals, carer relief and end of life 'sits' with patients and relatives if needed. In the north and west of the county this support is through North Northumberland Hospice and Tynedale Hospice at Home respectively (although the MCST try and help where able).

There is bereavement support from Macmillan Support Services, Specialist Palliative care teams, North Northumberland Hospice and Tynedale Hospice at Home and St Oswald's Hospice. There is an identified Northumbria Community Team key worker for each patient receiving support.

Are there gaps?

There is a shortage of carers, particularly in rural areas, limiting the availability of care packages and opportunity for residents to be managed in their own home. There is access to community hospital palliative care beds dependent on area e.g. Haltwhistle community hospital in the west, though outside core hours, patients may initially get admitted through an acute bed.

If a patient requests a private room at end of life every effort is made to ensure this, although unfortunately there is not a guarantee, due to bed capacity issues.

Ambition 2 - Each person gets fair access to care

"I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life."

Building Blocks to Achieve this Ambition

- Equality of palliative and end of life care regardless of where patients live or their life circumstances, in particular focussing on black, Asian and minority ethnic (BAME) patients, those with learning difficulties or non-malignant chronic conditions, and those patients living in rural or deprived communities.
- Address variations in access to good palliative and end of life care related to different care settings e.g. home vs hospice

What we have discovered?

When we reviewed place of death roughly 50% of all deaths are within a hospital setting and this is a consistent trend across the years.
Of the deaths in a hospital setting, 10% occur within the Specialist Palliative Care Unit or a Community Hospital which would be classified as a hospice death.
The data also indicates that over half of patients are supported to die in their preferred place of care/death.

We also reviewed deaths according to rurality. Approximately half die in hospital (including Alnwick, Berwick and Haltwhistle community hospitals); there are very few deaths in hospices though this may be expected given their urban locations.

As part of this analysis, we also reviewed the causes of death. The most common category of death across Northumberland is cancer, of which lung cancer is the top cause. For deaths which occurred at home (whether own home or care home) the most common cause was 'Frailty of Old Age'. For deaths in hospital the most common cause was pneumonia.

We are also able to review distances travelled from usual home address to place of death which showed that the average distance travelled (as the crow flies) was 9.3km, 7.4km and 7.6km for the years 2017-2019. This respectively demonstrates the distances travelled have reduced over the last few years, which suggests that end of life care is being delivered closer to home.

With regards to availability of support services there are Specialist Palliative Care Nursing teams, Therapy staff and Social Care Services based in Alnwick (North), Hexham (West) and Ashington/Blyth (South Central).

Macmillan Support Services are based in North Tyneside Hospital providing bereavement, befriending and information support for patient/carers across all of Northumberland. This service is led by Northumbria Healthcare Trust co-ordinators and supported by volunteers to provide on-going support. This support includes bereavement support, advice re benefits and befriending services such as 'walk and talk' groups for patients to meet others in similar situations.

Macmillan Care Support Team (MCST) provide 'hands on' care to palliative and End of Life patients 24/7 to enable them to remain in their own home. This service is made up of trained healthcare assistants. The cover is primarily for South/Central area though limited support is possible for residents in the North and West areas. MCST also links in with North Northumberland Hospice and Tynedale Hospice at Home to support patients in North and West Northumberland. There is also support given to palliative and end of life patients from District Nursing teams and Specialist nursing teams (e.g. heart failure nurses) based in a variety of bases but covering all of Northumberland. There is also palliative care provision across all of our hospital sites, namely Cramlington (NSECH), Ashington (Wansbeck), Blyth, Alnwick, Berwick, Hexham and Haltwhistle. Marie Curie and St Oswald's hospices also provide inpatient and day support for Northumberland palliative care residents.

What are we doing well?

In primary care, palliative case findings incorporate cancer and non-cancer diagnosis e.g. frailty of old age and chronic long term conditions and these patients are reviewed in MDTs within practices and increasingly at a primary care network (PCN).

In the West, a Palliative Care Partnership conducts an annual death audit within general practice, which promotes learning from deaths e.g. review of number of patients who died at their preferred place of death. Northumbria Healthcare Trust (NHCT) take part in regular death audits, including the National Audit of Care at the End of Life (NACEL) and FAMCARE (which measures family and carer satisfaction with their palliative care).

The consistent use of Emergency Health Care Plans (EHCPs) and Do not attempt cardiopulmonary resuscitation (DNACPR) helps to avoid inappropriate admission to acute setting to support patients dying in their preferred place of care.

There is support for all palliative patients regardless of diagnosis or area from GPs and all NHCT services including Community Nurses and Specialist Palliative Care Teams across all of Northumberland. There are information leaflets given to patients to explain all palliative care services available and includes the Macmillan Support Services bereavement leaflet.

For learning disabled patients with palliative care needs, there is support from a Macmillan Learning Disability community nurse, the Macmillan mental community nurses and the Northumbria inpatient learning disabilities nursing team

Are there gaps?

There are variations in support in areas of Northumberland, for example the North has North Northumberland Hospice Care, and the West has Tynedale Hospice at Home; in South and Central Northumberland the Macmillan Cancer Support Team (MCST) provide a similar service.

The community hospitals at Haltwhistle, Alnwick and Berwick can accept direct palliative care admissions though this is restricted to normal working hours between

Monday to Friday, outside of this time patients are required to go via NSECH. Deaths that occur in these community hospitals, which serve the more rural communities of Northumberland, would be classified as hospice deaths. as would those that occur in the specialist palliative care unit at Wansbeck, serving the South-East part of our county. Due to the geography of Northumberland, it would not be feasible to build a hospice to serve all of the residents of Northumberland, especially when patients and their loved ones want their end of life care provided closer to home. The focus therefore has to be on delivering the highest quality palliative and end of life care as locally as possible, whether that is in the patient's own home or one of the local hospitals in accordance with the patient's own wishes.

We recognise the challenges in engaging with harder to reach groups; there are, however, easy read resources available for residents with a learning disability and translated resources for those residents whose first language is not English. However, we are rolling out passports to My Health and Wellbeing for patients with mental health affected by cancer to help navigate support and treatment.

Ambition 3 - Maximising comfort and well being

"My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible."

Building Blocks to Achieve this Ambition

- Skilled assessment and symptom management.
- Access to specialised palliative and end of life care when required.
- Addressing all forms of distress, alongside physical symptoms, such as psychological, social or spiritual.

What we have discovered?

Across Northumberland the palliative care experience of patients and their families is collected both in the hospital and community setting. The information for the palliative care ward at Wansbeck will be available as an Appendix. The unit regularly receives ratings from patients of 'very good' or 'good'.

Regarding training for our healthcare professionals, there is the Palliative Care Academy to support with the education and training of staff to promote the care of palliative care patients. There is a rollout of prescribing training for all Specialist Palliative Care nurses, so they can prescribe palliative drugs which will ensure palliative care patients receive symptom control in a timely and appropriate manner.

There is psychological support from the Specialist Palliative Care team for all palliative care patients. There is chaplaincy support for in-patients. There is social work and care manager support for clients/patients including Macmillan Social workers in all areas.

For urgent referrals into the Palliative Care service there would normally be a response within 24 hours (or less) and for non-urgent referrals approximately a week. All patients who have appropriate needs are supported. For less complex cases their palliative care needs are often met by community nurses, social care or occupational therapy.

What are we doing well?

Community nurses and GPs all have experience in managing palliative care patients. The community teams work with support from Macmillan nurses and have good links with community palliative care consultants. There is same day referral to community palliative care team (Monday to Friday 9am-5pm and a 24-hour phone line for advice). The community nurses undertake holistic assessment as part of end of life care.

Northumberland has a particularly active voluntary and community sector which works very much in partnership with palliative care services.

The additional support and capacity which they offer is very much valued within the Northumberland system. An appendix will be published which details the Voluntary agency support in Northumberland for the range of range of VSCE providers across the area.

Are there gaps?

There is training offered by the Palliative Care team to GPs, community nurses and hospital ward staff depending on need, although the training is not mandatory for all staff groups.

There are some differences in palliative and end of life care provision between Northumberland and North Tyneside. In both areas there is provision from 8.30am-5.00pm - Monday to Friday with Specialist Palliative Care service including Nurses, Consultants and Therapists. However, in North Tyneside, there is also a commissioned urgent response (within 1 hour) specialist palliative care nursing service (PCNS) from 9.00am until 7.00pm, 7 days per week including bank holidays. This urgent service responds to crisis situations such as symptom control, pain management, carer stress/breakdown, to support the patient to remain in their own home, and many of the calls are regarding symptom control. The PCNs service in North Tyneside is made up of nurses who are independent prescribers who can prescribe medication when needed, without the need of an Out of Hours GP. In Northumberland not all palliative care nurses are prescribers, although the service is working towards this, and there is not any out of hours PCN support. Therefore, if a patient is suffering symptoms, it would necessitate a call to an Out of Hours GP which can cause delays for the patient due to the pressure of calls and the geography of Northumberland.

There is also a Hospital Liaison Team (HLT) which is based on 3 main Trust sites (WGH, NSECH and North Tyneside) and they currently work Monday to Friday 8.30am-5.00pm. The service provides support to all wards but particularly to the emergency department at NSECH to try and prevent unnecessary hospital admissions and to get patients safely back to their preferred place of care. This service is not routinely available on weekends/bank holidays, although the team have tried to provide some cover at weekends/bank holidays on a voluntary basis which has proven to be invaluable and supported the flow of patients significantly as well as giving a quality service. There is also a North East Ambulance Service (NEAS) palliative care ambulance that conveys patients from hospital to their preferred place of care though again this is not a seven-day service.

Interestingly, data shows that there are consistently half the number of palliative patients from North Tyneside in comparison to Northumberland admitted to hospital. Although there are multifactorial reasons for this it is felt that the North Tyneside urgent response element of the Palliative Care Nursing Service has contributed significantly to these results.

There is the hospice advice line which operates over evenings and weekends, where health professionals can obtain palliative care advice from both specialist nurses and the on-call palliative care consultant.

However, there is also a national target to provide remote clinical advice to health professionals overnight as well; this 24/7 service is not currently available within Northumberland.

Ambition 4 - Care is coordinated

"I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night."

Building Blocks to Achieve this Ambition

- Care records which set out patient's needs, and preferences are shared with their consent, with all those involved in their care.
- Care is optimised using a system wide multi-disciplinary team approach.

What we have discovered?

The coordination of care is delivered through consistent use of multidisciplinary team (MDT) meetings which are open to palliative care services. The hospital MDTs happen weekly, to discuss patients open to the palliative care service and ensure services around the patient are joined up. These MDTs include consultants, nurses, social workers, occupational therapists, physiotherapists and technical instructors. Where required, there are joint home visits with GPs, Community Nurses and Specialist Palliative Care staff.

The teams within our community health can quickly and easily share medical records as the majority use the same computer system. The social care records are held using a differing system and are shared with the residents and family where appropriate.

What are we doing well?

The teams within primary care, community nursing, palliative care and community hospital use a shared clinical system (SystmOne) which promotes continuity of care. Patient paper plans (e.g. EHCP, end of life pathway documentation) are transferable from community to hospital and back with the patient.

The EHCP/DNAR/ADRT documentation are shared with NEAS, Out of Hours GP, GP practices, community nurses, care agencies, relatives, community hospital, hospice and palliative care teams with consent.

EHCP are often written in conjunction with the palliative care team, and where necessary specialist teams such as haematology, heart failure or respiratory nurse specialists and hospital consultants. There is an electronic referral process for GPs, DNs, consultants and other professionals to refer into the palliative care service. There is a single point of access (OneCall) for all referrals to social care with one telephone number for all of Northumberland.

In the West there is the palliative care partnerships which improves the coordination of working, and reviews care carried out via the death audit to support future learning.

Are there gaps?

The records between health and social care cannot currently be shared due to incompatibilities in the computer systems. In practice this results in a health professional who needs social care information calling One-Call and a social care professional who needs health information calling either the community nursing or GP practice.

While a majority of Northumberland GP practices use SystmOne there are a few practices on a different clinical system (EMIS) which prevents easy sharing of information with other community facings teams. Furthermore, care plans are often in paper form which could potentially limit the sharing of information across the system in a timely and appropriate way.

Ambition 5 - All staff care

"Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care."

Building Blocks to Achieve this Ambition

- All staff, at every level, delivering palliative and end of life care are trained, supported and encouraged to provide high quality care.
- All staff involved in palliative and end of life care must understand and comply with relevant legislation that seeks to ensure an individualised approach e.g. Mental Capacity Act, safeguarding responsibilities.
- Every organisation should have clear governance at board level for high quality palliative and end of life care.

What we have discovered?

All Community Nurses, GPs and hospital staff have mandatory training on the mental capacity act, safeguarding and deprivation of liberty (DoLS). The Specialist Palliative Care Team staff all undertake training in palliative and end of life care. The staff also train GPs, DNs, Social Care and acute staff in ensure they are prepared to care for palliative and end of life. There are clear governance processes in place for both social care and Specialist Palliative Care teams about clear escalation of information/treatment plans as required.

Staff have the opportunity to reflect on deaths including collection of case studies (Full details will be published as an Appendix).

What are we doing well?

Our experienced specialist palliative care teams support the wider health and care teams in palliative care and end of life pathways.
As mentioned earlier, there are a range of support teams including the Macmillan Support Services and Macmillan Care Support Services

All community nursing and GPs have experience in managing palliative care patients. For example, some matrons have previously worked as Macmillan nurses. There are opportunities for community and primary care teams to reflect following a death. Each GP practice has a named clinical lead for palliative care. In the West, this lead attends the palliative care partnership.

The Macmillan support services, and specialist palliative care teams provide holistic care to each individual. The patient experience surveys have highlighted the positive feedback that patients have given both in acute and community settings. It has demonstrated the compassionate care within the organisations involved.

Are there gaps?

End of Life care training is not yet mandatory for all hospital staff, but it is hoped that on the back of the NACEL (National audit for care at the end of life) report that this

will become mandatory. The Palliative Care Hospital Liaison team has developed a training passport for general ward staff to complete and evidence palliative care training.

Ambition 6 - Each community is prepared to help

"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well, and to support each other in emotional and practical ways."

Building Blocks to Achieve this Ambition

- Voluntary organisations are supported and valued as part of the system wide multi-disciplinary team approach.
- Improve public awareness of the challenges patients face and a better understanding of the help that is available for palliative and end of life care.
- Promote public health approaches to palliative and end of life care e.g. Dying Well Community Charter.

What we have discovered?

There are well established joint working and contract arrangements between Northumbria Healthcare Trust and other palliative care organisations such as North Northumberland Hospice, St Oswald's, Marie Curie and Tynedale Hospice at Home. There are links and referrals made to other voluntary agencies including Cruise, Winston's Wish, Darcey's Dream, FACT, Barnardo's Mosaic and Orchard projects. In the West, Tynedale Hospice at Home, Lifespan, cancer support group, Northumberland carers all attend the Palliative Care Partnership. Other examples of working across communities include the community matron undertaking education sessions at local Women's Institute, around planning for the future and a good death.

There are a range of voluntary sector organisations who are actively engaged in palliative and end of life care. This includes a range of bereavement services who offer additional support before and after death (Full details will be published as an Appendix).

As part of this strategy review, we sought the views of the residents of Northumberland on palliative and end of life care. The engagement report (full details will be published as an Appendix) has highlighted that many residents are reluctant to talk about death and dying. In this regard a number of 'Death cafes' have been held in Northumberland, with the objective of increasing awareness of death with a view to helping people make the most of their lives. It allows a range of members of the community to attend and discuss the subject in a supportive environment. There has been positive feedback from these 'Death cafes' and as a result there are more planned.

There are information hubs for palliative and cancer sufferer patients to enable them to access relevant information when needed. There are support planners within social care who are able to signpost patients and provide information on services. Leaflets are available to patients/carers on what support is available.

What are we doing well?

We work closely with a number of voluntary sector organisations in support of palliative and end of life care, and they provide an invaluable resource to Northumberland residents.

Are there gaps?

From the engagement report, a significant number of Northumberland residents do not feel ready or willing to talk about death and dying. This is a complex and sensitive topic area which needs to be approached through our strategy.

We are also aware that the care and voluntary sector are under significant resource pressure. The availability and consistency of this valuable resource can vary across Northumberland but is integral to providing excellent palliative and end of life care to our Northumberland residents.

Section 2 – What we need to address

The mapping exercise in section 1 has demonstrated the depth and breadth of palliative care and end of life services across Northumberland. The second part of the strategy development involves identifying best practice, county-wide variation (where it exists) and gaps in the provision of services. This will objectively inform what we as a system need to prioritise to ensure residents of Northumberland receive the highest quality palliative and end of life care when needed.

In the table below we have summarised best practice, regional variation and gaps in service provision for the six National Council for End of Life ambitions:

Ambition	Best Practice	County-wide Variation	Gaps in Service Provision
Each person is seen as an individual	Well established palliative care registers An emphasis on proactive care Good bereavement support	There is a shortage of care staff in rural areas limiting opportunities to be cared in own home	Access to community hospital palliative care beds is during working hours only
Each person gets fair access to care	Learning disability nurses provide support for learning disabled patients with palliative needs There are information leaflets for palliative patients: easy read and translated		We need to ensure harder to reach groups e.g. BAME community, are aware of what palliative care services are available
Maximising comfort and well being	There is good access to urgent and non-urgent palliative care support during core hours. A holistic approach is adopted when assessing patients palliative care and end of life needs		Single room in hospital for end of life care cannot be guaranteed The specialist palliative care service does not operate over weekends in the community.

			There is no access to overnight palliative care advice for health professionals. NEAS palliative care ambulance only operates during working week
Care is coordinated	Multi-disciplinary team (MDT) working is well established. Emergency Health Care Plans (EHCP) are recognised across the system. There is a well-established culture of information sharing across the system		Care plans are often paper based which potentially limits their ability to be shared across the system
All staff care	Evidence demonstrates compassionate care across all organisations There is training available for all staff: both mandatory and optional		End of life training is not mandatory for all hospital staff
Each community is prepared to help	There is well established working with the voluntary care sector (VCS) Death cafes have received positive feedback	The VCS often work on a local rather than county-wide footprint	Some Northumberland residents do not feel ready or willing to talk about death and dying

Section 3 – Our Palliative and End of Life Care Priorities

This section sets out our palliative and end of life care priorities so as to embed best practice, close regional variation and address gaps in service provision. This will ensure we achieve our vision of all of our residents in Northumberland receiving the highest quality palliative and end of life care.

Ambition	Priority	Outcome Measure
Each person is seen as an individual	We will develop pathways to allow access to community hospital palliative care beds 24/7 with appropriate clinical assessment	Community hospital palliative care bed admission pathway for 24/7 access
Each person gets fair access to care	We will work closely with community and voluntary groups to ensure views from the diverse range of groups representing Northumberland residents are heard and acted upon.	Engagement with our broad and diverse communities across Northumberland
Maximising comfort and well being	To improve access to single bedrooms where requested for end of life care. Support recording of preference for single bedroom. Improve access to specialist palliative care in both hospitals and the community outside core hours. Improve access to palliative care advice including overnight in line with national recommendations To improve availability of palliative care ambulances at the weekends and out of hours	The option to offer single bedroom rooms when requested for end-of-life care Increased provision of specialist palliative care support outside core hours both within hospital and the community Ensure palliative care advice to health professionals is available 24/7 either by phone or video consultation. Increased availability of palliative care ambulances to convey patients to their preferred place of care/death
Care is coordinated	To promote multidisciplinary team working between health and social care providers. To support electronic sharing of information between health and	Ensure effective MDT working is established across all GP practices in Northumberland Electronic information sharing platforms are

	care providers to support palliative care provision including discharge and care plans	available and accessible to all health and care workforce
All staff care	Appropriate level of best practice training is available and taken up by all relevant health and care staff including consideration of communication training on difficult conversations around death and dying	Improved uptake of best practice palliative care training (mandated or optional dependent on staffing group)
Each community is prepared to help	Increase availability of discussion forums such as “Death Cafes” to support development of community action Rollout in our “community” so residents understand our vision of providing the highest quality palliative and end of life care when needed	Wider roll-out of “Death Cafes” Increased public awareness of our “community commitment”

Section 4: What does success look like

We need to give consideration to how we measure the success of our strategy in ensuring all of our residents in Northumberland receiving the highest quality palliative and end of life care and how this care is maintained.

A **Northumberland End of Life and Palliative Care Monitoring Group** will be convened. This Monitoring Group will meet regularly to monitor performance, recommend areas for improvement and implement required changes across the End of Life and Palliative Care pathway. This Monitoring Group will be formed with stakeholders from across the health and care system, voluntary sector and be public facing. Terms of reference will be established, with agreement of all stakeholders. It is expected this group will meet at least once per year.

The remit of the Monitoring Group is expected to cover:

1) Ensuring all Northumberland residents have access to palliative care support at the time they need it.
2) Ensuring promotion of 'our community commitment' across Northumberland so residents know what they can expect if they need palliative and end of life care.
3) Regular review of whether we have delivered on our palliative and end of life care priorities to embed best practice, close any regional variation and address gaps in service provision.
4) Understanding of the full End of Life pathway and appreciation of people's preferences at End of Life.
5) Highlighting and addressing any inequalities identified within access to End of life and palliative care.

The monitoring group will review a range of qualitative and quantitative data sources including:

1) Patient, carer and staff surveys across Northumberland.
2) Activity and Outcome Data from community and hospital services including preferred place of care/death, access to services, effectiveness of interventions access to private room for end of life.
3) Comparative data such as Office of National Statistics, Mortality Database and regional data.
4) The Northumberland Public Health Tableau End of Life and Palliative care dashboard.