**NEWHAM WELLBEING PARTNERSHIP**

**END OF LIFE CARE STRATEGY FOR ADULTS**

**2020 - 2023**

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| *“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die”.* Dame Cicely Saunders[[1]](#footnote-1) |  |

1. **INTRODUCTION**

Approximately one percent of the UK’s population dies each year; and within that population the majority of deaths can be predicted. The provision of high-quality, equitable End of Life Care (EoLC) is a key national and local priority for Health and Social Care. This is reflected nationally in the Government’s commitment that ‘every individual nearing the end of their life should expect a good death: attentive, dignified and compassionate care’[[2]](#footnote-2); and locally with the East London Health and Care Partnership (ELHCP) prioritising improving EoLC across the footprint.

The Ambitions for Palliative and End of Life Care: A National Framework for Local Action 2015-2020[[3]](#footnote-3) and NICE quality standards End of Life Care for Adults[[4]](#footnote-4) and Care of Dying Adults in the Last Days of their Life[[5]](#footnote-5) provide a robust foundation for improving the experience of care for adults as they approach the end of their life.

Based upon current performance, Newham has further to travel to achieve these ambitions than other areas.

To improve this, the Newham Wellbeing Partnership[[6]](#footnote-6), in collaboration with individuals who have personal experience of dying and bereavement, have co-designed this Strategy, identifying the key areas of improvement required to better enable individuals approaching the end of their life, their families and professionals to recognise, prepare for and manage the end of life process. This will enable individuals to be cared for and die in their place of choice and ensure appropriate and timely bereavement care is available for their families.

Newham is ethnically diverse, with 72.9% of the population from a Black, Asian or Ethnic Minority (BAME) background. Within such diversity there are differing beliefs and customs about health, illness and death. The challenges and subsequent areas of improvement identified within this Strategy seeks to acknowledge and understand this complexity: noting that bettering outcomes for the Newham population requires the fostering of cultural competency of Health and Social Care professionals involved in delivering EoLC. Taking the time to understand each individuals’ unique cultural beliefs, values and needs is the most respectful way of delivering EoLC and facilitating a dignified death.

This aim supports the Council in achieving Priority 5: Quality of Life of the Council’s Corporate Plan - ‘improving our Health and Social Care system so it works for Newham residents’.

The focus of this Strategy is EoLC for adults, as the circumstances surrounding the death of a child / young person and the care and support required for both them and their families requires a different approach.

1. **END OF LIFE DEFINITION**

For the purpose of this Strategy and in line with the General Medical Council’s definition[[7]](#footnote-7), individuals are considered to be approaching the end of their life when they are likely to die within 12 months. This includes individuals whose death is imminent (expected within a few hours or days) and / or those with:

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

EoLC is care that ‘helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the palliative care needs of both the patient and loved ones to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support’.[[8]](#footnote-8)

1. **NATIONAL CONTEXT**

There were 533,253 deaths registered in England and Wales in 2017, a 1.6% increase from 2016 and the highest number registered annually since 2003[[9]](#footnote-9). Nationally, the population is both growing and ageing, when taking this into account, mortality rates decreased slightly from 2016 to 2017. Mortality rates for cancers and respiratory and circulatory diseases have also decreased. However, rates for mental health needs, such as Dementia, and diseases of the nervous system, such as Parkinson’s have increased. This could be partly linked to a better understanding of these conditions - leading to increased identification and diagnoses; and also to individuals living longer and developing these conditions, which are often related to aging.

A proportion of this number (approximately 25%) will not require EoLC because the cause of death is sudden, either through unpredictable onset of disease or an external cause.

The National End of Life Strategy (2008)[[10]](#footnote-10) radically raised the profile of EoLC in England, signaling the need for development in planning and delivery, to ensure that individuals are able to exercise genuine choice in how and where they are cared for and die. To support the implementation of this Strategy, within London, the Association of Directors of Adult Social Services (ADASS) made EoLC a priority work-stream; and in 2014/15 produced an EoLC Charter[[11]](#footnote-11).

Following this, the National Palliative and End of Life Care Partnership, made up of statutory bodies (including NHS England and ADASS) and independent organisations representing patients and professionals was established and developed a framework for action in making palliative and EoLC a priority at a local level.

Ambitions for Palliative and EoLC: A National Framework for Local Action 2015 - 2020sets out six ‘ambitions’ - principles for how care for those approaching end of life should be delivered, from an individual’s perspective:

* each person is seen as an individual;
* each person gets fair access to care;
* maximising comfort and wellbeing;
* care is coordinated;
* all staff are prepared to care;
* each community is prepared to help.

**TRAJECTORY OF DEATH**

The Cohort Model[[12]](#footnote-12) identifies three distinct illness trajectories for individuals with progressive chronic illnesses:

1. a short period of evident decline, typical of individuals withCancer;



### a gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected death, typical of individuals with organ failure associated with Long Term Conditions;

### https://seniorserviceannouncement.files.wordpress.com/2012/03/1020-5-iline_default.gif

### a prolonged dwindling, typical of frail elderly individuals or those with Dementia.



Thinking in terms of these trajectories provides a broad timeframe and patterns of probable needs and interactions with Health and Social Care that can, conceptually at least, be mapped out towards death. Such frameworks may help clinicians and practitioners plan and deliver appropriate care that integrates active and palliative management: acknowledging that different models of care will be appropriate for individuals with different illness trajectories. Furthermore, if individuals and their families gain a better understanding by considering their illness trajectory this may help them feel in greater control of their situation and empower them to cope with its demands.

As such, one of the key areas of improvement within this Strategy is to develop, document and implement an EoLC pathway for the three illness trajectories. There is also an emphasis on early identification of individuals through pro-active case finding in order to maximise the opportunities to plan care in advance and ahead of a crisis.

**END OF LIFE QUALITY ASSESSMENT TOOL (ELCQUA)**

Data relating to end of life is collated and held by the Office of National Statistics - and the National End of Life Care Intelligence Network has developed an online self-assessment tool, ELCQuA, designed to support local service improvement and commissioning of EoLC services.

Of the data collected, the most commonly used to measure EoLC performance is the proportion of individuals:

* who are on a Palliative Care Register - identifying those who are approaching the end of their life is imperative to provide time to plan proactively around their wishes: placing an individual on a Palliative Care Register has been shown to lead to better and coordinated EoLC[[13]](#footnote-13);
* who have an electronic Advanced Care Plan - once identified and communicated to the individual, advanced care decisions can be made, communicated and shared among those delivering care (with the consent of the individual);
* who have a number of non-elective (emergency) admissions in the last 90 days of life;
* Those who die in their usual place of residence and those who die in hospital – recorded as place of death can be a critical contributor to the quality of death for an individual and their family and friends, as research suggests that most individuals, when asked, would prefer to be cared for and to die at home (or usual place of residence) - impacting on their psychological, physical, social and spiritual comfort and the possibility for family and friends to be present during the final days and hours of their life.

There are difficulties in measuring if the preferred and actual place of death match for any individual unless they have their preference and place of death recorded on Co-ordinate My Care (CMC), the preferred EoLC electronic Care Plan for the London and North East London population. A significantly higher proportion of people with a completed, and shared, CMC record die in their preferred place of death (PPD) and this is usually their ‘usual place of residence’ recorded as Death in Usual Place of Residence (DiUPR). A further indicator that is available is the proportion of individuals dying in hospital, and decreasing numbers suggest that individuals’ preferences are being met more often. However, generally the London population who die at home (or in their usual place of residence) is significantly lower than the England rate.

**BEREAVEMENT CARE**

Grief is a universal response to the loss of a loved-one; however, it affects all individuals differently. When an individual is bereaved they often have to cope with a world that can feel as if it’s fallen apart and as such their grief can affect them emotionally, physically and / or mentally. In addition, in practical terms, their life may have changed dramatically (e.g. living alone, having less money, faced with household tasks they haven’t done before, etc).

Prolonged and / or undealt with grief can lead to exhaustion, interfere with an individual’s ability to think clearly (make decisions / judgements and problem solve), leave them with feelings of loneliness or isolation all of which can affect their immune system, trigger anxiety attacks and depression; and in some cases trigger substance misuse.

Bereavement care is an essential component of EoLC that includes anticipating grief reactions and providing ongoing support for the bereaved over a period of 12 months.

Good palliative and EoLC includes giving care and support to those who are important to the dying individual. This must encompass good bereavement and pre-bereavement care, including for children and young people. It must also respond to the needs of those who are affected by death caused by sudden illness or trauma, including suicide. As well as caring for them as individuals who are facing loss and grief, there needs to be recognition and support for their role as part of the individual’s caring team, if they and the dying individual wish them to be regarded in that way.

1. **EAST LONDON HEALTH AND CARE PARTNERSHIP (ELHCP) CONTEXT**

The ELHCP work across the seven CCGs within North East London and have established a work programme to deliver improved end of life care, a key priority across the footprint. This includes an End of Life Programme Board and a number of work streams which will engage with both health, care and wider community representatives. There is a strong and complimentary fit with the developing Ageing Well Strategy of the London Borough of Newham. The current priorities of the ELHCP include the (five year) Long Term Plan for Palliative and end of life care and this is in development. Key priorities are:

To clearly understand local need both now, and for the coming years. To achieve this we will need to understand the impact of, and on our services so that we can fit the local need within our population. This will include factors such as the needs of individuals who have no recourse to public funding, and experience social and economic deprivation, isolation, social marginalisation, loneliness and the effect of rapid population change (Newham has a high degree of population churn).

To be able to deliver personalised care, and personal health budgets which can offer greater choice and flexibility in end of life care support. This is a particularly important factor because we have a diverse community, which encompass a wide range of belief systems that may impact on how end of life care is offered and delivered.

To agree a model of care that can deliver integrated services within a collaboratively agreed model of care that is place based and therefore accessible locally, in our residents own community, and capable of better supporting care at home. This will require improved working and supporting capacity and capability within the community. These are key factors in influencing choice on where care is delivered and in supporting avoidable hospital admission where the preference is for care at home. Success will mean that there is a single and responsive access point for palliative and end of life care support to individuals who will have a shared care record which, if their consent is given, will avoid unnecessary repeated history taking as well as reducing duplication of cost and effort across the wider health and social care system.

To be accountable to our population and ensure that we use public funding to maximum effect and ensure transparency.

To develop and implement a comprehensive North East London EoLC education and training programme so that our carers, care homes, community health and care services, and GP Practices are supported to confidently have difficult conversations and consider their end of life care choices in timely manner.

To develop an implementation plan with clear milestones and metrics for taking forward the recommendations set out in the Government’s response to the End of Life Care Choice Review[[14]](#footnote-14), in collaboration with partners and with our citizens and patients.

The ELHCP work stream provides the opportunity to both standardise practice across a wider geographical area served by one acute Trust.

1. **LOCAL CONTEXT**

Newham is the third largest borough in London with a population of 359,470 (and unweighted GP registered population of 412,352 (August 2019)).

Newham has a transient population with an estimated churn of 20.6%: with individuals leaving or arriving into the borough (not including births and deaths).

The adult population is 74% of the total population at 258,021; however, it is the sixth youngest borough in the country with a median age of 31.6 years and second youngest in London[[15]](#footnote-15).

Although Newham has a younger than average population, its residents show signs of early ageing; and have a significant period of unhealthy life before death - leading to a higher than expected burden of disease on Health and Social Care services.

The proportion of residents aged 75 and over is currently just above 7%, but the demographic trend is for a significant growth of older adults over the next 10 years, and within this those aged 85 and over will increase the fastest.

Culture, ethnicity and religion has a fundamental influence on an individuals’ views on advanced planning, preferred place of care and death and EoLC interventions (e.g. desire for life-sustaining treatment).

Newham is a diverse borough with 72.9% of the population from a BAME background; and 27.4% of the population a Non UK-National[[16]](#footnote-16). Consequently, there are a variety of religions practiced and over 240 languages spoken within the Newham population.

This creates a number of challenges for Health and Social Care professionals when supporting individuals approaching the end of their life, in terms of:

* cultural / religious values conflicting with the concept of advanced planning. Discussing death is actively discouraged in some cultures as it is viewed as an indication of disrespect, likely to extinguish hope, invite death and / or cause distress, depression and anxiety;
* understanding of the UK’s Health and Social Care system - and care and support options (e.g. the alternatives to hospital-based care and support);
* approach to communicating end of life diagnosis, with some cultures wishing to ‘protect’ those approaching the end of their life from hearing their diagnosis;
* English being a second (or third) language and how this may impact on an individual’s understanding their condition, diagnosis and care and support choices available to them - preventing ability to make informed decisions.

In 2017, the last full year for which Mortality Cause of Death Data is available, 1,350 Newham individuals died. Of these 1,138 were over the age of 55.

The main causes of death for this over age 55 population in highest order were: Coronary Heart Disease and Circulatory Disease; Malignant Neoplasm (Cancers); Dementia; and Diabetes.

**ILLNESS TRAJECTORIES**

Cancer

Cancer is a disease caused by an uncontrolled division of abnormal cells in a part of the body; and accounts for approximately 25% of all deaths in Newham, with breast, colorectal and lung cancers being the leading cause of all Cancer mortality.

Each year in Newham, 756 individuals are diagnosed with Cancer of which 341 will die from the disease. 30% of Cancers are diagnosed through the emergency route, as opposed to 23.7% national average. This implies that diagnosis of the disease needs to be earlier.

In 2018/19, there were 4,068 registered patients in Newham living with a Cancer diagnosis[[17]](#footnote-17).

Newham has the 5th highest mortality rate for all Cancers across London; and the second worst one-year survival rate for Cancer in England. Whilst Newham residents are no more likely to get Cancer than anywhere else, this means that those who do are far less likely to still be alive one year after diagnosis than almost any other Local Authority area. Factors that contribute to late detection include poor public awareness of Cancer symptoms leading to low uptake of screening and late presentation to a GP; and factors related to the Health service including delays in primary and secondary care.

Organ Failure

Organ Failure is the failure of an essential system in the body. Multiple organ failure is the failure of two or more systems, such as the cardiovascular and renal systems. For the purpose of this Strategy, the Partnership’s focus, within this trajectory, is Chronic Obstructive Pulmonary Disease (COPD) and Heart Failure.

In Newham during 2017, 173 individuals[[18]](#footnote-18) (of all ages) died from a respiratory disease. This includes COPD for which there is no specific published data at present. This figure represents about 12% of those who died during 2017.

Figures for Heart Failure are being updated and will be added to a subsequent version of this document.

In 2018/19, there were 3,539[[19]](#footnote-19) registered patients in Newham living with a COPD diagnosis and 2,070[[20]](#footnote-20) registered patients in Newham living with a Heart Failure diagnosis.

Dementia

Dementia is a chronic progressive neurodegenerative illness which has a terminal outcome over an average range of three to eight years.

In Newham, 285 individuals died from Dementia in 2017.

In 2018/19, there were 1,079[[21]](#footnote-21) registered patients aged 65+ in Newham living with a Dementia diagnosis, with a further 500 estimated to have Dementia but not received a formal diagnosis. The diagnosis rate is slightly above the NHS England benchmark, with 71.7% of individuals having been diagnosed, against an NHS England rate of 66.7%.

Nationally, EoLC for individuals with advanced Dementia has been poorly researched, and service provision in the UK is generally poor. It is important that we undertake further research on the number of deaths in the usual place of residence for Newham residents in order to explain our position as an outlier: the Public Health England data for 2017/18 record this as just 39.1% for Newham residents, against a figure of 86.1% in the best of our CCG benchmarking comparators. This suggests inequitable care when compared with a similar CCG cohort.

**FRAILTY**

Frailty is related to the ageing process; and describes how ones’ bodies gradually lose their in-built reserves, leaving us vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection or a change in medication or environment. In Newham, frailty exists in all age groups and is not exclusive to the older adult population.

Researchers have demonstrated that there is a linear relationship between increasing frailty and increased odds of mortality[[22]](#footnote-22). Increasingly, it is recognised that progressive frailty, either Moderate or High, using the Electronic Frailty Index (eFI), is a precursor to dying.

The **eFI**, developed by the University of Leeds, TPP (System One), Bradford Teaching Hospitals NHS Foundation Trust, Bradford University and Birmingham University, is an evidence based criteria for identifying frail patients. It is based upon 36 deficits comprising 2000 read codes (in the GP Practice Record). The score is strongly predictive of adverse outcomes (e.g. falls, disability, admission to hospital, or the need for long-term care) and has been validated in large international studies.

The eFI score is out of 36. For example, if nine deficits are present then the score will be 9/36 or 0.25. In this way the following frailty categories can be defined:

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| **eFI Score** | **Category** |
| 0 - 0.12 | Fit | People who have no or few long-term conditions that are usually well controlled. This group would mainly be independent in day to day living activities. |
| 0.13 - 0.24 | Mild Frailty | People who are slowing up in older age and may need help with personal activities of daily living such as finances, shopping, transportation. |
| 0.25 - 0.36 | Moderate Frailty | People who have difficulties with outdoor activities and may have mobility problems or require help with activities such as washing and dressing. |
| > 0.36 | Severe Frailty | People who are often dependent for personal care and have a range of long term conditions. Some of this group may be medically stable but others may be unstable and at risk of dying within 6 - 12 months. |

The current number of individuals living in Newham, registered with a Newham GP who have been identified as having a moderate to high frailty score is 5,780. This position was accurate at the 1st April 2019.

The ELHCP is currently looking at the emergency hospital activity, in both Accident and Emergency and in non-elective admissions associated with these specific diagnoses. An analysis will be added to the next iteration of this document.

**PALLIATIVE CARE REGISTER / CO-ORDINATE MY CARE (CMC) PLANS**

As of April 2019, there were 308 patients recorded a Practice Palliative Care Register in Newham with fewer than 40 recorded as having an Advanced Care Plan. The Palliative care register has been increasingly superseded by Co-ordinate My Care (CMC)

At April 2019, there were 1,344 patients with a Coordinate My Care (CMC) Plan[[23]](#footnote-23): with 484 of these have been added in the preceding 12 months.

**PLACE OF DEATH**

Newham is below the national average for the proportion of individuals enabled to die at home (22% compared to 46.8% nationally) and considerably above the national average for the proportion dying in an acute hospital (60.8 compared to 45.7%)[[24]](#footnote-24). The disparity for individual’s with dementia are even more concerning as identified earlier within this Strategy. Moreover, a significant majority of Newham individuals who die experience three or more emergency admissions in the last year of their life. The position is illustrated in Graph 1 below.

The Newham population, benchmarked against the North East London, London and England population is shown below in Graph 1. The data, illustrated below, shows that of all the CCGs within the ELHCP footprint, Newham, although more recently beginning to demonstrate progress, has consistently shown the lowest number of deaths in the usual place of residence, among the seven CCGs / Boroughs within the ELHCP footprint since 2011 /12.

 GRAPH 1: NORTH EAST LONDON - PERCENTAGE OF DEATHS IN USUAL PLACE OF RESIDENCE

Graph 2, below, illustrates the trend in respect of the number of acute, non-elective (emergency) admissions into hospital within the final 90 days of life across the seven CCGs that comprise the ELHCP across North East London. The Newham position (2017) shows the highest position of emergency admissions at just above 9%:



GRAPH 2: EMERGENCY ADMISSION INTO HOSPITAL IN THE LAST 90 DAYS OF LIFE

**7. NEWHAM CHALLENGES**

Dying and death are taboo topics for many. Often individuals do not want to acknowledge their own mortality, can’t find the words to use when it comes to talking specifically about their own death or feel uncomfortable talking to others about their financial affairs, cultural and religious beliefs, etc. However, failing to discuss and plan for dying in advance often leads to unnecessary suffering and challenges (e.g. not having pain medication in place to enable care to happen at home, not having a Lasting Power of Attorney in place prepared for losing capacity and preferences not being communicated, etc).

In order to improve end of life experiences for individuals in Newham, residents, families, communities and professionals need to normalise the way they talk about dying, death and bereavement - empowering honest and ‘difficult’ conversations and emphasising the importance of having these as early as possible.

The Newham Wellbeing Partnership have together noted the many and various gaps in the pathway and EoLC service provision is currently fragmented and displays evidence of a clear lack of communication, integration and partnership working.

Local data and feedback from a variety of stakeholders suggests:

* lack of resident and professionals’ awareness of advanced care planning tools - and therefore individuals having these in place;
* a lack of clarity across Health, Social Care and the independent sector about who is responsible for the clinical identification of an end of life prognosis, their confidence to deliver this identification and knowledge of the next steps to ensure appropriate and timely care and support is provided in line with the individuals’ needs and wishes;
* disparity in engagement with advanced planning between different ethnic groups;
* disparity in both the preferred and actual place of care and death for different ethnic groups;
* disparity in the care and support that is received by an individual dying of Cancer compared to those dying of COPD and Heart Failure, and in particular Dementia / Frailty;
* disparity in the care and support that is received by individuals who are asylum seekers / refugees, homeless, have a learning disability or have forensic mental health needs including dementia;
* disparity in the understanding and therefore the use of the various services available to support individuals approaching the end of their life (e.g. hospice purpose and criteria);
* availability of and capacity within specialist, palliative care provision;
* the confidence of generic front-line care staff (e.g. Domiciliary Care, Extra Care, Care Homes, etc) in providing care for individuals in their last days of life (anxiety of the individual approaching the end of their life, managing challenging behaviour, understanding and supporting through the process of death, etc);
* variation in how and when fast-track applications for end of life care is applied with evidence of high numbers of fast track applications, indicative of late identification or recognition of the dying person;
* variation in timely prescribing of anticipatory medication and Medication Authorisation Records which may contribute to people unnecessarily experiencing pain and with distress to care givers at the end of life;
* East Ham Care Centre EoLC beds having an acute hospital registration with the CQC contributing to high numbers of acute hospital deaths that may not accurately reflect the experience of the dying person and their family;
* insufficient understanding and recognition around feelings of isolation and loneliness - not wanting to die at home alone.

Since commencing the development of this Strategy, a number of improvements have been made in Newham. For example:

* an EoLC GP Clinical lead has been appointed;
* baseline data (2017/18) of individuals aged 65 and over who have died in hospital and who had three or more acute episodes in the previous 12 months has been collated and analysed;
* a Community Bereavement Service has been commissioned and in place since the 01.08.2017;
* the Integrated Community Equipment Service is able to identify when an order is for an EoLC customer and are committed to same-day delivery for orders for EoLC Customers (and can provide narrative regarding the reason/s for when the timeframe is not met);
* £25,000 awarded from the CEPEN for EoLC training, with a specific focus on Primary Care and Care Homes, offering up to 15 Practices and their MDTs Silver Standard EOL Care Training and to all Care Homes (Older People), Gold Standards EOL Training and accreditation;
* fixed-term funding allocated for an EoLC Champion to be a contact point for planned care and death in the individual’s usual place of residence, and who would work across Primary, Community and Social Care to effect change and support the dying individual in achieving the preferred place of care and death. In addition, this role will sustain learning across Health and Social Care practitioners through facilitating after death analysis at the MDT level;
* the Integrated Carers Support Service specification has been revised, with the Provider to advise of advanced planning tools, as part of Emergency Planning discussion;
* a pathway and relationship has been built between the Care Homes (Older People) and ELFT Rapid Response service to negate, where appropriate, the need for Customers to be taken to the hospital;
* a frailty workstream has been identified via the Building Healthy Communities programme – to better identify and support residents with a moderate and severe frailty score.

**8. NEWHAM PRIORITIES - KEY AREAS FOR IMPROVEMENT**

To address these challenges, the Newham Wellbeing Partnership is committed to:

* raising awareness of dying, death and bereavement - empowering residents to understand, discuss and record their preferences around EoLC prior to long-term illness. This should also act as a driver to improve overall service quality, as individuals begin to broach the topic with Health and Social Care professionals;
* developing and implementing an equitable EoLC pathway, regardless of each illness trajectory, led by primary care in partnership with Barts NHS Trust, East London Foundation Trust and the Council;
* developing and promoting a single, comprehensive and user-friendly EoLC resource on Care in Newham for individuals and Health and Social Care professionals;
* ensuring that the NHS Long term Plan requirements are incorporated into our actions, and demonstrable synergy with the ambitions of the East London Health and Care Partnership Palliative and End of Life Care Programme Board;
* supporting and upskilling the borough’s generic and specialist workforce to be able to have honest, informed and timely conversations with individuals about dying, death and bereavement; and to provide appropriate and compassionate care in the last days of life;
* mandating CMC, as the single and shared electronic Care Plan used by Health, Social Care and the independent sector for recording the wishes of those approaching the end of their life;
* auditing and if necessary improving the completion of CMC Care Plans so they are complete, relevant and accessed by those who will be delivering them;
* early identification of those people who may be approaching the end of life through Primary Care case- finding using validated search tools. These tools may need to be developed to better meet the needs of our Newham population where we may have evidence of increased frailty at a younger age;
* improving communication with the individual approaching the end of their life (and their Carers / family, as requested by the individual) and across the organisations delivering EoLC and support;
* improving 24/7 availability and knowledge of EoL pain medication in the community;
* reviewing and re-procuring the Community Bereavement Service that responds to the needs of individuals affected by the death of a loved one/s.

It is imperative that these actions are shaped and delivered within the Newham context: with Health and Social Care professionals being aware of, competent in and sensitive to individuals’ cultural, ethnic and religious differences and how these may influence the views of individuals around advanced planning and their preferred place of care and death and EoLC interventions.

**9. OUTCOMES / SUCCESS CRITERIA**

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| Outcome 1 | Increase in the number of patients identified on the Primary Care Palliative Care Register (from 304 baseline); |
| Outcome 2 | increase the number of patients with a CMC Plan and the quality of the completed plan (from 1,344 baseline); |
| Outcome 3 | improvement in the provision of responsive and appropriate 24/7 Health and Social Care services across Newham; |
| Outcome 4 | increase in the proportion of individuals approaching the end of their life receiving care in their preferred place of care and dying in their preferred place of choice (from the current low baseline); |
| Outcome 5 | personalised care, and greater use of personal health budgets to ensure a better experience and choices of how and where to receive end of life care and where to die for individuals and their loved ones; |
| Outcome 6 | a more confident Health and Social Care staff able to undertake ‘difficult conversations’ and provide appropriate care and support in the last days of life; |
| Outcome 7 | the Newham Wellbeing Partnership being able to evidence that death, dying and bereavement is everyone’s’ business. |

**10. ACTION PLAN**

This Strategy provides an Action Plan (Appendix A), based upon the ambitions that will be implemented over a three-year period by an EoLC Strategy Group.

The Group will comprise Partnership and resident representatives, as well as key voluntary sector organisations.

It is hoped the implementation of the Action Plan will support the Partnership to create and embed a solid foundation to improve EoLC across the borough, acknowledging at the end of the Action Plan period that further work will be required to address nuances in delivering EoLC for specific cohorts (e.g. individuals who are asylum seekers / refuges, those who are homeless, those with a learning disability and those with forensic mental health needs).

Progress toward the Action Plan will be monitored by the Newham Wellbeing Partnership Board and reported through the Health and Wellbeing Board.

1. <https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1> [↑](#footnote-ref-1)
2. <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf> [↑](#footnote-ref-2)
3. <http://endoflifecareambitions.org.uk/> [↑](#footnote-ref-3)
4. <https://www.nice.org.uk/guidance/qs13> [↑](#footnote-ref-4)
5. <https://www.nice.org.uk/guidance/ng31> [↑](#footnote-ref-5)
6. The Council, Newham CCG, Barts Health NHS Trust, East London Foundation Trust and Newham Health Collaborative are working together to develop an Integrated Care System (ICS). The intention of the ICS is to deliver innovative and seamless care that improves the health and wellbeing of the population of Newham - through all Health and Social Care stakeholders working together collaboratively, enabling the ICS to effectively and efficiently plan, co-design, commission and deliver ‘the right care, in the right place, at the right time’. Newham’s ICS is called the Newham Wellbeing Partnership. [↑](#footnote-ref-6)
7. <https://www.gmc-uk.org/-/media/documents/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf> [↑](#footnote-ref-7)
8. <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136442/EOLC_equality_assessment.pdf> [↑](#footnote-ref-8)
9. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2017 [↑](#footnote-ref-9)
10. https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life [↑](#footnote-ref-10)
11. https://londonadass.org.uk/wp-content/uploads/2014/12/LSCPFinalCharterEoL.pdf [↑](#footnote-ref-11)
12. <http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/understanding_trajectories_of_illness_and_cohorts_of_need> [↑](#footnote-ref-12)
13. <https://www.gponline.com/gps-role-end-of-life-care/palliative-end-of-life-care/article/1366021> [↑](#footnote-ref-13)
14. <https://www.ncpc.org.uk/sites/default/files/CHOICE%20REVIEW_FINAL%20for%20web.pdf> [↑](#footnote-ref-14)
15. <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland> [↑](#footnote-ref-15)
16. <https://www.newham.info/population/> [↑](#footnote-ref-16)
17. NELCSU 2019, Clinical Effectiveness Group- Newham Commissioning Report [↑](#footnote-ref-17)
18. Public Health England - Fingertips [↑](#footnote-ref-18)
19. <https://fingertips.phe.org.uk/search/COPD#page/1/gid/1/pat/46/par/E39000018/ati/165/are/E38000113> [↑](#footnote-ref-19)
20. <https://fingertips.phe.org.uk/search/organ%20failure#page/1/gid/1/pat/46/par/E39000018/ati/165/are/E38000113> [↑](#footnote-ref-20)
21. <https://app.powerbi.com/view?r=eyJrIjoiM2Y0ZTUzMDUtMmYzOC00MDUxLWE1YTUtMjRhYzVkZjVlODRjIiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOjh9> [↑](#footnote-ref-21)
22. <https://www.sciencedaily.com/releases/2019/02/190219133013.htm> [↑](#footnote-ref-22)
23. The seven North East London CCGs have agreed CMC as the Advanced Care Plan of choice - and have paid for access and support of record completion. At present this can be viewed and updated by GPs and London Ambulance Service. There are plans for it to be made available across Bart’s Health, the acute Provider across East London and eventually Newham Council - providing opportunity for one standardised Health and Social Care Advanced Care Plan for individuals approaching the end of their life. [↑](#footnote-ref-23)
24. National End of Life Intelligence Network: Newham Profile [↑](#footnote-ref-24)