

**Royal Borough of Kensington and Chelsea  
Adult Social Care and Health Select Committee**

**12 October 2023**

**NW London adult community-based specialist palliative and end-of-life care for adults (18+) review programme:**

This paper aims to:

- Provide a comprehensive update on the progress made by the programme team since our last presentation to the Royal Borough of Kensington and Chelsea, Adult Social Care and Health Select Committee on 29 November 2022.
- Seek your support and gather your opinions on the proposed new model of care before officially launching the engagement process.

As key stakeholders, we highly value your ongoing involvement and collaboration in this programme.

[www.nwlondon.nhs.uk/cspc](http://www.nwlondon.nhs.uk/cspc)

NHS North West London programme team last attended the Royal Borough of Kensington and Chelsea, Adult Social Care and Health Select Committee on 29 November 2022. Since then, the NW London community-based specialist palliative care new model of care working group, has been diligently working to co-produce and agree the proposed new model of care for adults' (18+) community-based specialist palliative care.

The new model of care working group included residents of seven out of eight boroughs (excluding Hounslow). Starting from May 2022, the model of care working group has met 38 times and successfully concluded their discussions on 6 June 2023.

The engagement approach and the work of the model of care working group have been recognised as best practice by the North West London Integrated Care Board (ICB). The feedback from the working group members about their participation, the approach taken, the transparency of the programme team, and the outputs of the working group has been overwhelmingly positive.

For instance, one of the 12 patient representatives on the group, who is also a clinician working in NW London, expressed that being part of the group and engaging in the discussions has significantly enhanced her understanding of palliative and end-of-life care. This knowledge has directly influenced and improved her practice, leading to better outcomes for the patients she has supported with palliative and end of life care needs.

On 22 August 2023 we published our first draft of the proposed new model of care for adults (18+) community-based specialist palliative care on our NW London Integrated Care System (ICS) website. We wrote to partners in North West London sharing this documentation to gather feedback on the proposed new model of care and make sure that we were on the right track or if there was anything else we needed to consider.

As well as launching a simple online survey, we have also held three North West London wide engagement events in September 2023 about the model of care. In partnership with local borough based partnerships, we have subsequent engagement events commencing Monday 2 October 2023 through to Thursday 5 October. This includes a bi-borough specific event being held on Monday 2 October 2023, from 1.30pm to 3pm.

On 14 September 2023, we attended the North West London Joint Health Overview Scrutiny Committee to provide an update about the model of care and answer questions from committee members. On the 18 September 2023, at the request of a number of public members who are part of the new model of care working group, we met with them and a number of additional interested members of the public and Central London Community Healthcare NHS trust (CLCH) (who provide the Pembridge palliative care services at the St Charles Centre for Health and Well-being).

The aim of this session was to have an open dialogue regarding the challenges and any opportunities about Pembridge in-patient unit. The unit has been suspended

since 2018 due to difficulties with recruiting and retaining a palliative care consultant to support safe operation of the inpatient unit. This was a constructive meeting and a further meeting will be held on the 09 October 2023 to progress the dialogue that has started.

During the meeting CLCH highlighted the actions they have taken to support recruitment including:

- September 2018 to date\* – attempts to recruit locum Consultant in Specialist Palliative Care to cover Pembridge beds – unsuccessful
- October 2018 – Locum Consultant in Rehabilitation Medicine with experience in SPC as a junior doctor recruited, but following a supervised probation period of 2 weeks, arrangement was discontinued due to safety concerns leading to suspension of admissions to the inpatient unit
- September 2018 - February 2019 – Substantive Consultant for inpatient post advertised and recruitment process – unsuccessful in recruiting to post
- March - May 2021 – Discussions with Imperial Hospitals and St John's Hospice to recruit to cross site SPC Consultant roles – suspended as acute colleagues could not support the proposition
- May 2022 – July 2022 – Internal service development to enhance appeal of role in Pembridge unit, including additional Consultant leadership role within the service. Put in place by increasing current locum PA allocation.
- June 2023 – November 2023 - Consultant Job Description updated and will be progressed to recruitment after internal and Royal College of Palliative care approval.

To date, ongoing efforts to recruit a locum Consultant in Specialist Palliative Care to cover Pembridge inpatient beds have been unsuccessful due to:

- Shortage of Consultants in SPC wanting to work in Hospice settings
- No availability of locums willing to individually or collaboratively work the number of days required to safely run the
- inpatient unit
- No availability of locums willing to commit to longer than a three-month contract
- Uncertainty about the future of the unit

An action for the NHS NW London programme team from the Royal Borough of Kensington and Chelsea, Adult Social Care and Health Select Committee in November 2022 was to provide results of the survey given to families who had been offered alternative services to the Pembridge.

In 2022/2023, 94 patients from Pembridge palliative care services catchment area received specialist inpatient care at alternative hospices that are commissioned by North West London. These include St Luke's Hospice, St John's Hospice and Royal Trinity Hospice. The majority of these patient were supported at St. John's Hospice in-patient unit. In 2021/2022, 102 patients in the same catchment areas were supported at alternative hospices, with St. John's Hospice again supporting the majority of these patients.

Whilst recognising the importance of engaging with these individuals and their family to understand their views and experience of receiving care at these alternate hospices as opposed to the Pembridge in-patient unit, it has proven challenging to engage with these individuals and to hear their views and to date we have not received any response to the survey that asked our hospice providers to support with disseminating This is for a number of reasons:

- **Complex and Challenging Care:** Patients who require hospice in-patient care have the most complex palliative and end-of-life care needs. This is a challenging and emotionally charged time for both patients and their families/care givers and those important to them. During this period, they have to absorb a lot of information and address numerous questions related to the patient's current needs and treatment. As a result, filling out surveys about their experiences is often not a high priority for them.
- **Emotional and Sensitive Context:** Patients admitted to hospice in-patient units are often very unwell, and some may pass away during their stay. Engaging with patients who are seriously ill and their grieving loved ones during this emotionally charged and sensitive time can be difficult for the staff during the admission as well as engaging with the loved one's post death.
- **Identification of Patients:** There is also a challenge in identifying and accessing these patients for engagement. The finance team responsible for the NW London program can track these patients separately, but the delivery teams providing care on the ground may not easily recognise them as "Pembridge in-patient unit catchment patients." This lack of recognition makes it challenging to reach out to them for feedback at the time of admission.
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We will however continue to try to engage with these patients and their families/ caregivers and those important to them throughout this programme of work, and hope to hear more from these individuals at the local borough based partnership engagement events.

### **North West London's proposed new community-based specialist palliative care model of care for adults (18+)**

#### **Our vision and aims**

North West London residents and their families, carers and those important to them have equal access to high quality community-based specialist palliative and end-of-life care and support, that is coordinated, and which from diagnosis through to bereavement reflects their individual needs and preferences.

We want to make sure service provision is sustainable and that we can continue to deliver the same level of high quality care in the future.

The proposed new model of care encompasses several core service lines designed to make sure we can improve equity and accessibility. These are underpinned by a

number of key principles and enabler also agreed upon by the model of care working group, and are in line with best practice, engagement feedback and national guidance. These services include:

**1. Care in your home**

- Community Specialist Palliative Care (SPC) team providing support at home, including support to care homes
- Hospice at home service
- 24/7 specialist palliative care telephone advice

**2. Community Inpatient bed care:**

- Enhanced end-of-life care beds
- Specialist hospice inpatient unit beds

**3. Hospice outpatient and well-being services:**

- Hospice multi-disciplinary team outpatient clinic appointments
- Dedicated Bereavement and psychological support services
- Lymphoedema services
- Other day care and well-being services provided in the main by charitable hospices

In 2021, we recognised there was a need to carry out a review of community-based specialist palliative care services because it was the most fragile part of all the palliative and end-of-life care services (generalist and specialist) in NW London. We identified eight key issues we needed to address and published an [Issue Paper](#) that set out these reasons and engaged with local residents and partners to find out what was important to them.

Our aim is to develop a new model of care for adult community-based specialist palliative care that will help us deliver high-quality services for the next five years and provide the foundation for the longer term. Beyond this we will make sure our services have sufficient flexibility to increase service provision against a projected growth in demand, as and when that arises.

A model of care is a framework that explains what care will be provided and how services work together to deliver care that meets the needs of the population and incorporates best practice. Providers will then use the framework to deliver care with the expectation that we improve overall care for people. A model of care will bring together regulatory, organisational, clinical and financial factors to outline the way in which care will be delivered locally.

The role of the model of care working group has been to jointly co-produce a future model of care for community-based specialist palliative care for adults (18+ years) in NW London with advanced or life limiting conditions, collaboratively agreeing “what good looks like’ and setting a common core offer across the various services. The group also collaboratively agreed the design principles.

Some of the services within the new model of care already exist across all boroughs, while others are new additions. This is particularly significant for boroughs where the services currently do not exist or there is significant variation for boroughs. The recommended model of care would deliver the following for all NW London adult residents for the first time:

## **Service area 1: Care at home**

- Adult community specialist palliative care team:
  - 7-day service with working hours of 8 am - 8 pm – this is a change from 9am - 5pm working hours and some services (Harrow) only operating 5 days a week at present.
  - Increased support to care homes – common core level of training and support.
- Hospice at home:
  - Supporting up to 24-hour care at a patient's home (including overnight sitting services) in close collaboration with usual community care teams. This is currently not being provided across all existing services.
  - Expansion of services to additional boroughs currently without this service: Hammersmith & Fulham, Ealing, and Hounslow.
  - 24/7 specialist telephone advice line - a common core service for patients who are already known to community-based specialist palliative care services as well as unknown patients. This is a change from current 24/7 specialist palliative care advice line services, which in the main only support known patients and have variation in the level of advice and support offered.

## **Service area 2: Community specialist in-patient beds**

- An increased number of beds in the community, which includes dedicated enhanced end-of-life care beds available across all of NW London for patients who either do not require a hospice bed but cannot stay at home due to medical and social needs, or who do not wish to stay at home, or who do not want to, or do not meet the need to be in a hospital.
- Maintaining the current number of operational hospice in-patient unit beds to support our patients with the most complex specialist palliative care needs.

## **Service area 3: Hospice out-patient services, hospice day care services and well-being services (including psychological and bereavement support services for patients and families)**

Whilst all our boroughs currently have access to hospice out-patient clinics, hospice day care services and well-being services via their local providers, variation in the level of support provided was identified:

- We aim to make sure hospice out-patient multidisciplinary team (MDT) clinics (including but not limited to medical and nursing clinics, rehabilitation via therapists, and dedicated lymphoedema services) deliver the same core level of service. This refers particularly to the boroughs of Ealing and Hounslow where doctor and nurse led clinics are currently not available via Meadow House Hospice, as well as Harrow where there is currently a gap in provision of lymphoedema services for non-cancer patients. We propose to expand lymphoedema service provision for these non-cancer patients in Harrow.
- We aim to make sure well-being services (including hospice day care support groups, family and carer practical support and education, complimentary

therapies, and dedicated psychological and bereavement support services deliver a core level of service. Particularly for psychological and bereavement support services for patients, their families, carers and those important to them which includes: a more streamlined pathway to access these services; increased personalisation of care for example offering one-to-one and group sessions, face-to-face and virtual support; and increased cultural and spiritual sensitivity to delivery of this care and support. While all boroughs currently have access to some psychological and bereavement services, this varies in level of support.

**Key Enablers: The successful implementation of the new model of care relies on several key enablers:**

- Effective use of data and digital optimisation in service delivery
- Workforce development and planning
- Organisational development and community-based specialist palliative care staff training
- Strong leadership and governance.

**Addressing the eight key issues**

The new model of care aims to address the eight key issues outlined in an issues paper published by the programme in 2021 which launched this work. By incorporating these issues into our ongoing engagement and co-production of the new model of care the model, we are committed to creating a more comprehensive and responsive community based specialist palliative and end-of-life care system for the residents of North West London.

We can demonstrate how both the process and resulting product of this work responded to the original eight issues highlighted below:

The eight key issues we need to respond to	Key examples of how the issue has been built into the approach or model of care
<p>1 <a href="#">Respond to future need</a></p>	<ul style="list-style-type: none"> <li>• Used data to model 5 and 10-year demand for community-based specialist palliative care services and applied this to current services to understand future service demand.</li> <li>• Examined feedback from national surveys and reports to explore changing public expectations on care at the end-of-life and included this in model of care development.</li> </ul>
<p>2 <a href="#">Address service variation</a></p>	<ul style="list-style-type: none"> <li>• Developed a new model of care that addresses the current variation in service offerings to residents across our eight boroughs to support improving equitable access to services to make sure everyone can access services more fairly and consistently.</li> </ul>
<p>3 <a href="#">Respond to inequalities</a></p>	<ul style="list-style-type: none"> <li>• Undertook a travel mapping exercise (travel analysis) to understand impact on communities travelling to</li> </ul>

		<p>current in-patient units. We will undertake further travel analysis as part of the next phase of this work to understand impact of proposed options to deliver the new model of care.</p> <ul style="list-style-type: none"> <li>• Made sure there was representation of different faiths/ethnicities in the NW London model of care working group and made sure our engagement strategy reaches our diverse communities.</li> <li>• The model of care working group have agreed five key enablers to support the successful implementation and delivery of the new model of care. Development of a strategy and plan for supporting organisations to achieve cultural competency so they can effectively provide care in line with the new model of care.</li> </ul>
4	<a href="#">Integrated delivery</a>	<ul style="list-style-type: none"> <li>• Care co-ordination has been recognised as being key element of the new care model, which includes making sure that appropriate information is shared among providers to support seamless delivery of care. Improving co-ordination will be embedded in to the structure as part of the implementation of the new model of care.</li> </ul>
5	<a href="#">Responding to feedback and engagement</a>	<ul style="list-style-type: none"> <li>• Involved patients, carers, clinicians and members of the public in co-producing the model of care, ensuring the voice of local residents is truly reflected in service design</li> <li>• Hosted various NW London and borough based events, culminating in published engagement reports which have fed into the model of care working group discussions and design principles.</li> </ul>
6	<a href="#">Align with policy &amp; best practice guidance</a>	<ul style="list-style-type: none"> <li>• Reviewed best practice and national guidance and integrated these within model of care working group discussions to shape and develop each core service offer</li> <li>• Actively engaged with other organisations, areas and systems who have been implementing new models to inform our local work.</li> </ul>
7	<a href="#">Financially sustainable</a>	<ul style="list-style-type: none"> <li>• Made sure financial sustainability is a key principle and key hurdle criteria within the programme to make sure that actions and development are not only impactful but enduring for the longer term.</li> </ul>
8	<a href="#">Recruitment and retention</a>	<ul style="list-style-type: none"> <li>• Engaged staff and care providers throughout development to ensure the future model of care is clinically sound and reflects good practice, making NW London an attractive place to work. Engagement will be ongoing through the development of the enablers and implementation phase of this work.</li> </ul>

What does this mean specifically for the borough of Kensington & Chelsea residents



## **Summary of service improvements for Kensington & Chelsea residents with the proposed new and improved model of care for community-based specialist palliative care services for adults**

The proposed NW London community specialist palliative care model of care for adults (18+) will deliver the following services for Kensington & Chelsea residents. Some of these services already exist but will have been expanded, whilst some of them will be available for the first time:

### **Adult community specialist palliative care team**

- This service already exists but the opening hours of this team will increase to 8am - 8pm from current 9am to 5pm. Kensington and Chelsea residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

### **Hospice at home**

- This service already exists, but will be improved with a common core offer which includes support up to 24-hour care at home (including overnight sitting) if needed in close collaboration with usual community care teams.

### **Community in-patient bed care**

- Kensington and Chelsea residents will have access to an increased number of beds in the community, which includes the introduction of dedicated enhanced end-of-life care beds for patients who do not require a hospice in-patient bed but cannot stay at home due to their needs, do not wish to stay at home, and do not want to or need to be in a hospital. These beds will be available to all boroughs of NW London. They are currently only available in Hillingdon.
- Kensington and Chelsea residents will continue to have access to specialist hospice in-patient unit bed care.

### **24/7 specialist palliative care telephone advice**

- Kensington and Chelsea residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospice and specialist palliative care providers.
- This existing service will be expanded to support Kensington and Chelsea residents who are unknown to the community-based specialist palliative care services. They will be able to call a local 24/7 specialist palliative care telephone advice line for the first time and receive advice and support.

### **Hospice out-patient multidisciplinary clinics and well-being services**

- Kensington and Chelsea residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support across NW London services
- Kensington & Chelsea residents will have improved access to bereavement and psychological support services with a common core

offer, including 1:1 and group support, and a clearer pathway to access these services.

The proposed care model aims to offer more personalised and culturally sensitive care to address the diverse needs of the entire NW London population, including the specific needs of Kensington & Chelsea residents and underserved communities.

The model seeks to achieve this through a number of design principles and enablers which support tailoring services to individual preferences, cultural competence training for staff, and actively collaborating with local organisations and partners.

The ultimate goal is to ensure fair access to high-quality community-based specialist palliative and end-of-life care for all Kensington & Chelsea residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

## **Next steps - formal engagement about new model of care**

We are currently engaging with members of the public and other stakeholders, seeking input from the public on the proposed model of care. During this engagement phase, we aim to engage widely and work with our public and stakeholders to:

- Provide an overview of the development process of the model of care
- Outline the contents of the model of care (What is the model of care NOT how and where it will be delivered), and seek feedback from the public on the new model of care.

While the engagement document will not present options for the delivery of the new model of care, it will emphasise the importance of a well-distributed service that ensures equal access to the necessary care.

People can respond to the model of care by completing [our simple survey](#)., emailing our team at [nhsnwl.endoflife@nhs.net](mailto:nhsnwl.endoflife@nhs.net) or attending local Borough Based Partnership events.

or attend the

Engagement on the model of care will continue throughout the summer and early autumn.

## **Next steps after this engagement phase –October 2023 onwards:**

- We will publish feedback received and potentially a revised model of care which has considered that feedback.
- We will explain the next steps of the process to support having this model of care agreed and implemented for NW London.
- The programme team will develop a long-list of options for delivery of the new model of care with the steering group doing the initial shortlisting.

We will then move to the next stages of making recommendations about options for any formal consultation should this be deemed necessary.

We will continue to work with NW London residents and stakeholders throughout this process and we are immensely grateful for the continued engagement and contributions which are vital to the success of this transformative initiative.

If you have any questions or require further information, please do not hesitate to contact us at [nhsnwl.endoflife@nhs.net](mailto:nhsnwl.endoflife@nhs.net).

## **APPENDICES**

### **Ten-year demand projections for in-patient hospice care**

To understand whether we have the hospice inpatient beds needed to serve the inpatient needs of our population, we have undertaken an analysis of future demand and compared this with

#### **The methods used for projecting future need**

1. Understand how mortality in NWL changes over the next 10 years based on national statistical studies and applying local data.
2. Apply the annual rate of mortality growth to number of people who may require palliative care.
3. Include additional allowance for needing to address unmet need i.e. people who are not currently accessing care but need it.
4. Apply the rate of growth to bed use over 10-year period.
5. Compare future bed use with available capacity to determine when and if the demand for beds exceeds available capacity.

#### **Mortality in our population**

- We anticipate increasing number of deaths each year, climbing from 12,300 in 2023 to 14,500 in 2033.
- This is driven largely by an ageing population. This is expected to result in a corresponding increase in number of people needing palliative care. In addition, there are likely to be people who are not receiving palliative care when they should be we refer to this as 'unmet need'.
- If we assume we steadily work to improve public awareness and meet the palliative care needs of our whole population, we expect the number of people with a palliative care need to grow from 31,000 in 2023 to 37,000 in 2033.

#### **Hospice inpatient demand**

- If we assume the demand for inpatient care grows proportionally to overall palliative care need and there are no changes to the length of time each bed is used each time it is used, we can expect the number of bed days needed to grow from approximately 15,000 bed days per year in 2023 to 18,000 in 2033.

#### **Conclusions arising out of analysis**

- If the number of beds we use does not change over time, we can expect to have space (capacity) for approximately 20,400 bed days each year.
- Comparing expected increase in demand with available capacity, we will have enough beds to meet our needs until 2031.
- Beyond this time, we would need to make adjustments to either demand or capacity.
- According to our data analysis and based on an assessment of unmet need and demographic growth, we do not require more specialist hospice in-patient beds than those currently being commissioned and used.

## Travel mapping and analysis

Hospice in-patient bed provision currently works on the basis of catchment areas. In some cases, they overlap with the catchment area of other hospices. To understand how accessible, the units are to our population, we undertook a travel mapping analysis.

We looked at travel times for people accessing their closest hospice in-patient bed care unit (by travel time) and found that:

- Average peak time travel was 40 minutes by public transport and 19 minutes by car (driving).
- Populations in south Hillingdon and Hounslow have among the longest travel times to a hospice in-patient bed care unit because of the absence of alternatives in the area.
- With Pembridge Palliative Care Services in-patient unit suspended, average peak time travel for the whole NW London population is increased (by three minutes for public transport and two minutes for car).
- Looking more closely at the population for whom Pembridge Palliative Care Service is the closest hospice in-patient unit (in terms of travel time), shorter travel times to access the unit were experienced, when open, compared with the overall population travel times. The current suspension increases this group of residents travel time by 12 minutes on public transport and six minutes by car. The travel times for this group to the next nearest hospice is 43 minutes by public transport and 23 minutes by car which is comparable to the experience of the whole population (see table below for more information).
- Broadly, our hospice sites are located in areas within close proximity of deprived communities. People living in these areas are not adversely impacted by longer travel times.

	<b>Average peak time travel when using public transport</b>	<b>Average peak time travel when driving</b>
All current in-patient units	40 mins	19 mins
All currently available in-patient units (reflecting suspension of services at Pembridge Palliative Care Services in-patient unit)	43 mins	21 mins
Travel times for those people where Pembridge Palliative Care Services is their closest in-patient unit (when Pembridge Palliative Care Services in-patient unit open)	31 mins	17 mins
Impact of on directly affected populations with Pembridge Palliative Care Services in-patient unit being suspended	43 mins	23 mins

## Respond to future need - meeting the palliative care needs of NW London's changing population

When we embarked on the review of community-based specialist palliative care one of the [eight issues](#) we needed to respond to was making sure that we developed services that met the future palliative care needs of NW London's changing population.

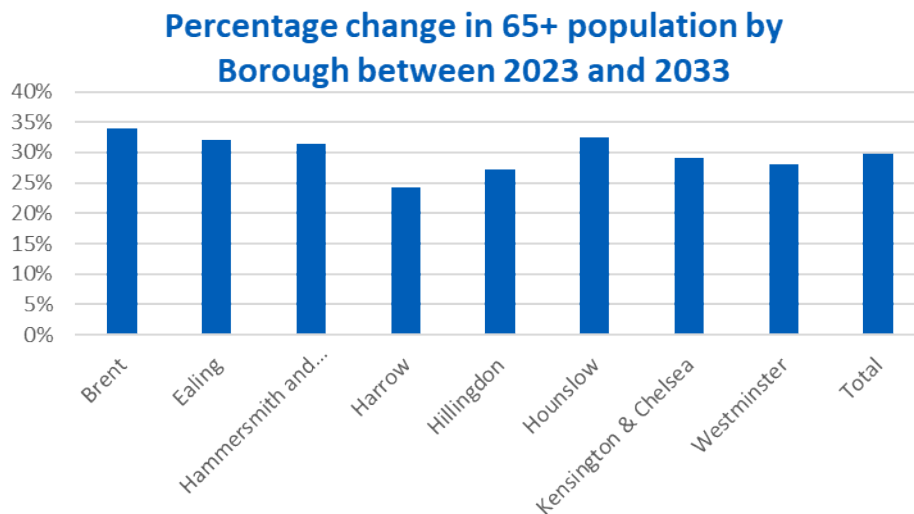
In order to do this, we committed to undertaking further demand modelling and population projections for a ten-year period to support future services modelling.

The outcomes of this work show that we can expect growth in hospice/ specialist palliative care service inpatient unit beds use to be in-line with the growth in the overall number of deaths in the NW London population over time. This is the result of an ageing population, population growth and a number of other factors such as increasing morbidity from chronic illness.

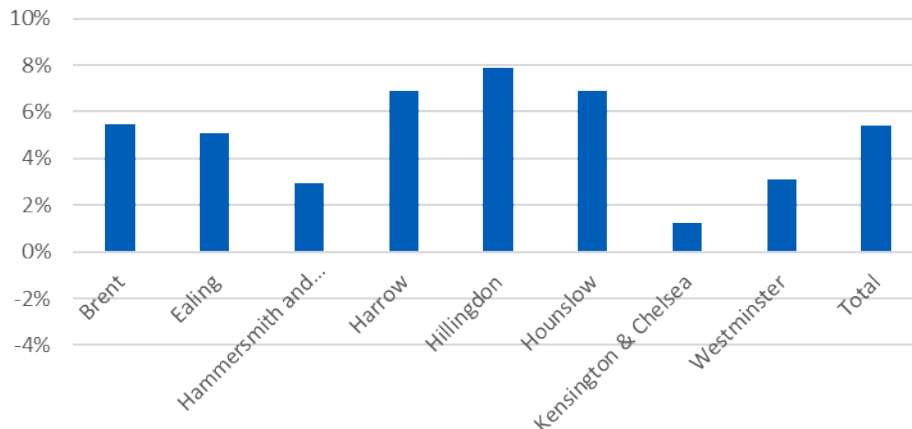
When we factor this in, we anticipate that we have sufficient of these specialist inpatient beds across our current hospices to accommodate local need for hospice specialist palliative care beds until 2031.

### How is our population likely to change over time?

We are expecting the population of NW London to grow by 5% over the ten-year period between 2023 and 2033, similar to the growth in population expected across London.



## Percentage change in population at Borough level over a 10-year period



During this time, the population size will grow from approximately 2.17 million people to 2.28 million. At this time, we anticipate the greatest growth in Hillingdon, Harrow and Hounslow.

Nationally, 85% of deaths occur in people over the age of 65 years. In NW London, the 65+ population is expected to grow by 30% over the same ten-year timeframe - a much faster rate than overall population. Looking further still, approximately 55% of deaths occur among the 80+ population and this group is expected to grow by 32% in NW London.

### How do we expect deaths to change over time?

Due to the impact of Covid-19 pandemic, we are cautious about applying mortality projections based on 2020 and 2021 data. In 2022 we recorded 12,111 deaths across NW London boroughs. Based on this, we expect annual deaths to increase to 14,587 by 2033.

This is impacted by ageing population and population growth and is based on the pattern of change modelled nationally.

### How many people need palliative care each year?



Across our eight Boroughs, we are responsible for the health and care needs of approximately **2.1 million** people. Of those, 1.7 million are aged 18-years and over.



As at February 2023, we have approximately **31,000 people** identified as potentially needing some degree of palliative care. We are also aware this may miss people who are unknown to us and estimate around **900 people** may not be included here.



In 2022 approximately 12,000 deaths were recorded for our registered population. Not all of these would be individuals who received specialist palliative care services

## What are the causes that contribute to this?

Leading causes of deaths among adults include dementia, ischaemic heart disease, chronic lower respiratory disease, stroke and cancer. You can find out more about leading causes of death through the [office of national statistics](#).

## Where do people die?

National data (see below) shows that at present around half of people die in a hospital, whilst just over a quarter die at home. A further 12% of people die in care homes and 5% die in hospices. The proportion of deaths in care homes and hospices has remained broadly similar over time. Whereas the proportion of deaths occurring in hospital has fallen and the proportion of deaths at home has increased over time, indicating potential changes in proactive end-of-life care planning and changing attitudes around remaining in the home environment.

While preferences on place of death haven't been collected locally, the National Survey of Bereaved People (2015) suggested 81% of people wished to die at home (a contrast to the 28% who actually die at home), 8% of people stated a preference for a hospice, 7% for a care home and only 3% for a hospital.

Public engagement has also highlighted that people change their mind or that their circumstances change, affecting their preferred place of death.

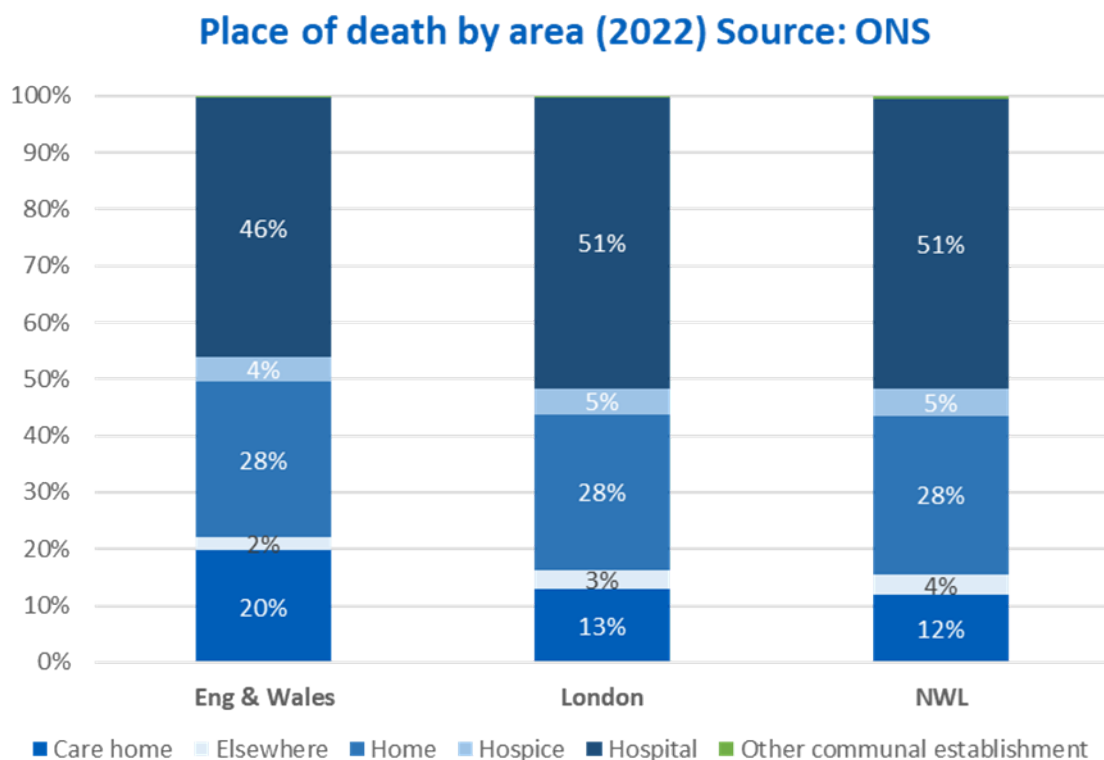


Figure 1: Source ONS 2022 (Death registrations and occurrences by local authority and health board)

The model of care group used the information to look at different ways to model future demand recognising that there is no exact way of predicting this, but with an



expressed desire to factor in unmet need (ie not just roll forward the activity we have now, increased to reflect population growth). This modelling approach shows we currently have sufficient numbers of the most specialist hospice in-patient beds across our current hospices to accommodate all patients who need this type of highly specialist support and care until 2031.

### **Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026**

Work is currently underway to map how the proposed new model of care would help address the six ambitions as laid out in the framework on a borough level.

## Summary of service for NW London residents

### Summary of service improvements for North West London residents with the proposed new model care for community-based specialist palliative care services for Adults

The proposed NW London Community Specialist Palliative Care model of care for adults (18+) would deliver for all North West London residents for the first time:

#### Care in your home:

- Community specialist palliative care SPC Team:
  - 7-day working hours (8 am - 8 pm) – a change from 9am - 5pm with some services which worked only 5 days a week.
  - Increased support to care homes – common core level of training and support
- Hospice at Home:
  - Supporting up to 24-hour care at home (including overnight sitting) in close collaboration with usual community care teams. This is currently not being supported across all existing services.
  - Expansion of services to additional boroughs currently without this service: Hammersmith & Fulham, Ealing, and Hounslow.
- 24/7 specialist telephone advice line – a common core offer including support for known and unknown patients.

#### Community inpatient care:

- Increased number of beds, which includes dedicated enhanced end-of-life care nursing home beds across all of NW London for patients who do not require a hospice bed but cannot stay at home due to their needs, do not wish to stay at home, and do not want to or meet the need to be in a hospital.
- Existing hospice inpatient unit beds to support our patients with the most complex specialist palliative care need.

#### Hospice outpatient and well-being services:

- Hospice outpatient MDT clinic and well-being services – a common core offer for the services this encompasses, including lymphoedema, bereavement, and psychological support services:
- Expansion of lymphoedema services for non-cancer patients in Harrow, addressing the current gap in provision
- Dedicated bereavement and psychological support services with common core offer– whilst all our services currently offer bereavement and psychological support this varies in offer and accessibility.

The proposed model of care aims to offer more personalised and culturally sensitive care to address the diverse needs of the entire NW London population. The model seeks to achieve this through a number of design principles and enablers which support tailoring services to individual preferences, cultural

competence training for staff, and actively collaborating with local organisations and partners.

The ultimate goal is to ensure fair access to high-quality community-based specialist palliative and end-of-life care for all North West London residents, while creating a supportive and inclusive environment throughout all aspects of care and services.