Community-based specialist palliative care for adults (18+):

Co-designing a new, improved model of care

An opportunity to give your views on how we best improve care

Update – 26 January 2024

The first draft of this document was originally published on 21 August 2023 and can be found here. Following an extensive period of engagement, we have edited and improved the model of care as documented here to take on board feedback provided – please see page 5 for a more detailed explanation of which parts of this document have changed.

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.

Version 2.0 – 26 January 2024

Contents

Revision statement covering changes made to the model of care following Autumn 2023 public engagement

Following the release of the model of care in August 2023, a series of nine engagement events took place in September and October at which members of the public, health professionals and other local stakeholders had the opportunity to comment on the proposals. Comments were also received via online surveys, email and in other face-to-face meetings.

Overall there was good support for the proposed new model of care, however we did hear some valuable challenges and constructive suggestions on how we might improve the model, which we committed to reflect in this revised version of the proposed new model of care. These included the following key themes:

More information about enhanced end of life care beds

There was an emphasis on provision of more detail and clear explanation of what will be offered in terms of these beds and how they will be made available to ensure that they effectively meet the needs of patients. Assurance was also sought that these beds are a suitable and high-quality option to meet a set of articulated patient needs, rather than a possible substitute for specialist hospice inpatient bed care.

Addressing inequalities

Feedback emphasised the need to address disparities in access, outcomes and experiences of palliative care services, ensuring that all individuals, regardless of their background or circumstances, receive the same level of high-quality palliative care. There were also calls for more tailored strategies for different communities, which considered geographic, socioeconomic, and cultural factors to demonstrate that the model will support addressing these disparities.

The need to enhance innovation and continue improvements to specialist palliative care services alongside the implementation of the new model of care

- Exploring innovative initiatives
    - Various feedback emphasised the opportunity to improve the model by exploring innovative initiatives, drawing on local, regional and national pilots already underway. Emphasis was also placed on making sure the current proposed model would remain open to testing the below ideas (which currently do not have enough evidence to support them being included in the current model) as pilots, whilst the model is being implemented:
        - Emergency department support via in-reach and rapid response, with aims to reduce admissions
        - Co-ordination service
        - Single point of access
        - Virtual hospice (which could include specialist MDT support)
        - Support for rapid discharge from hospital

- Improved navigation of services
    - Emphasis was placed on simplifying the complex journey through palliative care services and the wider health and care system for patients, families, carers and clinicians to make the services more accessible through, for example, enhanced information resources and a single point of access at NW London or local borough level.
- Enhanced care co-ordination and integration of services
    - Feedback emphasised the need for more seamless transitions between acute and community services, through more integration and co-ordination across acute specialist and community specialist palliative care services. More seamless transition was also emphasised within community palliative care services (spanning both generalist and specialist care providers) and social care services, particularly at local "place" level.
    - Improved communication and collaboration amongst healthcare professionals was also emphasised so as to support a localised, patient-centred approach with named care coordinators (or a dedicated care co-ordination service/function to improve the overall patient experience and bridge gaps between generalist and specialist care).

Improved leadership and governance

Feedback emphasised the need for robust leadership and governance structures to guide the proposed changes and for improved accountability and sustainability within the new care model.

This revised version of the model of care has been edited to reflect this feedback. Specifically, it features extensive changes to the following sections:

- 10.1d – Continuing service developments alongside implementation of the proposed new model of care to best support people at home
- 10.2 – Service area 2: Community specialist in-patient bed care
- 11.2 – Reducing inequalities in access, outcomes and experience
- 11.5 – Leadership, governance and integration

Each of these sections is highlighted within this document so as to be clearly distinguishable.

A number of more minor revisions have also been made throughout the model of care document to reflect feedback and, in some cases, corrections – these are also highlighted within the text where noteworthy.

1. Introduction

We are delighted to share with you the results of a journey we started in 2021 to shape the future provision of adult (18+) community-based specialist palliative care services in North West London (NW London). Community-based specialist palliative care services are part of a much larger pathway and picture for palliative and end-of-life care in NW London.

We also acknowledge this improvement work for community-based specialist palliative care services is in many ways a starting point and that more needs to be done to improve palliative and end-of-life care as whole, by which we mean the generalist services provided by a range of services in our hospitals, in the community and in general practice. Whilst some of this is being addressed in other NW London improvement programmes such as community nursing and care homes, there's still more that will need to be done in the future.

Only a small number of the population require these specialist services, whereas the majority of the population will need generalist palliative and end-of-life care support from other health and care services in the community. From the outset of this work we have been and continue to be committed to approaching this important topic in a way that brings together the needs and feedback of our communities, as well as making sure the approach incorporates clinical best practice and is evidence-based.

Over a twelve-month period, a group of NW London residents with lived experience of palliative and end-of-life care, as well as bereavement, along with clinicians and providers, were brought together into a model of care working group. The group met over thirty times to systematically co-design the services and support the development of a new, improved model of care that we believe will meet the needs of NW London residents for the next five years and beyond. This document represents the culmination of time and energy invested by a large diverse group of people and I am thankful to them for helping us get to this point.

Patient choice

Patient choice is important. And being able to make an informed choice alongside professionals underpins delivery of this model and improved quality and outcomes for our residents. This new model of care aims to make sure people have a choice, getting the right care, at the right time, by the right team and in the right place, alongside their wishes and preference. Through it, all residents, no matter their circumstances, will be able to access the services they need.

We are also tremendously pleased that the model of care has received the unanimous support of all the NW London hospices and NHS providers of community-based specialist palliative care services and was approved via the NW London community-based specialist palliative care steering group, which includes all charitable and NHS providers of community-based specialist palliative care services in NW London and some wider palliative and end-of-life care stakeholders.

We would like to express our gratitude to all the residents, families and carers who have given their personal time to work alongside us and challenge our thinking throughout. We are grateful to you for sharing your experiences, at one of the most difficult moments in your lives, to help improve the future experience of others. We shared this through the published engagement outcome report.

In our engagement and the work that we have carried out through the model of care working group, we have considered the needs of our diverse communities and those with protected characteristics including people who live with learning disabilities, and people who are experiencing homelessness and LGBTQI. in some cases, we carried out literature reviews and spoke to experts representing some of these communities. This insight was published in the engagement outcome report. Engagement will also continue and a full equality health impact assessment will be carried out in the future.

We would also like to thank the clinicians and providers who have engaged with us on model of care discussions, bringing their years of experience and knowledge to the steering and working groups. Lastly, we would like to thank our local authority partners for their insights and contributions. These have been invaluable in shaping the range of services and support that we are proposing should be delivered in NW London.

The model of care working group has been responsible for the development of the new, improved community-based specialist palliative care model of care and agreed the following principles that would be needed to deliver good care to our NW London residents:

- Increased personalised care based on the patients or individual needs.
- Increased cultural sensitivity in delivering care.
- Improved communication with patients and support networks.
- Increased partnership working and coordination among care providers.
- Increased use of technology to augment care delivery across all services lines.
- Making sure we fully use our workforce and their expertise to help them provide the best possible care and support to patients, families and those important to them.

The model of care working group found that there was, overall, good provision of community-based specialist palliative care services in NW London. We already have the key ingredients necessary to provide high quality specialist palliative care for those who need it towards the end of their lives. The services that are currently available meet the standards of good practice which are set out nationally.

However, we do have some gaps in service provision and opportunities to improve and level up care. We aim to provide the same core level of high-quality community-based specialist palliative and end-of-life care to all residents in NW London, regardless of their community or borough. Taking into account patients' medical and social needs and circumstances, our goal is to deliver this care in their preferred location in as much as possible.

It is important to acknowledge that despite the efforts of the supportive teams in the community to provide this care in alignment with patient preferences, a patient’s medical and social circumstances may limit their options for where they receive their care. Where it is not clinically safe for the patient or appropriate for those providing care to the patient, unfortunately, individuals may need to be moved to a different place of care where they can receive the appropriate care and support and ensure their safety and well-being.

NHS North West London (NHS NW London) and the model of care working group want all NW London residents to have consistent and equal access to:

- A wide range of high-quality community-based specialist palliative care services that helps patients to stay at their usual place of residence, but allows them the flexibility to move to a different care setting if it is needed.
- Extended service provision aligned to best practice and guidance, along with minimum common service standards.
- Specialist palliative care telephone advice available 24-hours per day, 7-days per week for residents and their families, carers and clinicians, whether residents are already known to the community-based specialist palliative care services or not.
- An increased range and number of community specialist in-patient bed care options, by introducing enhanced end-of-life care beds for people with less complex specialist palliative care needs who still require in-patient care, on top of the existing specialist hospice in-patient beds that we currently have.
- The right number of the most specialist hospice in-patient unit beds, to care for the patients projected to need this level of palliative care over the next five years and beyond.

We are satisfied that we have identified the key areas we need to address to improve community-based specialist palliative care for our residents. We have worked in a true partnership between local residents, health and care professionals and the charitable hospice and NHS providers to achieve this.

We can already see how these improvements could support patients and their carers, families and those important to them when facing the challenges of life limiting illness and the palliative and end-of-life care journey.

We now want to work with local residents and our partners to ensure the model of care and the wide range of services and support included within it reflects all that we have heard.

We look forward to receiving your feedback on the proposed model of care.

Dr Lyndsey Williams

Robyn Doran

Co-chair, community-based specialist care model of care working group
GP clinical lead for palliative and end-of-life care and care homes, NHS NW London

Senior responsible officer, community-based specialist palliative care programme and director of transformation, Central and North West London NHS Foundation Trust and Brent Integrated Care Partnership director and

Jane Wheeler
Co-chair, community-based specialist care model of care working group and director of local care, NHS NW London

2. Acknowledgments

This document has been produced by the NHS NW London programme team working on the community-based specialist palliative care review. The work reflects the recommendations of the NW London community-based specialist palliative care model of care working group, whose membership included:

- **Twelve patient representatives (local residents and carers with lived experiences of palliative and end-of-life care services)**
    - Marion Sumerfield
    - Emily Engel
    - Eugenie White
    - Sonia Richardson
    - Sally De Jongh
    - Atanaska Velkova
    - Madhu Jani
    - Amina Potter
    - Shawana Iram
    - Lorraine Ainscow-Searle
    - Bansari Rupani
    - Sneha Dewan
- **Our community-based specialist palliative care providers**
    - Harlington Hospice
    - St John’s Hospice
    - Royal Trinity Hospice
    - St Luke’s Hospice
    - Marie Curie Hospice (Hampstead)
    - Central London Community Healthcare NHS Trust (CLCH)
    - Central and North West London NHS Foundation Trust (CNWL)

    - London North West University Healthcare NHS Trust (LNWH)
- **Other key palliative and end-of-life care stakeholders within NW London integrated care system**
    - London Ambulance Service NHS Trust
    - NW London Continuing Health Care (CHC)
- **NW London programme team members**
    - Dr Lyndsey Williams, Co-chair, community-based specialist care model of care working group and GP clinical lead for palliative and end-of-life care and care homes, NHS NW London
    - Robyn Doran. Senior responsible officer, community-based specialist palliative care programme and director of transformation, Central and North West London NHS Foundation Trust and director of Brent Integrated Care Partnership
    - Jane Wheeler, Co-chair, community-based specialist care model of care working group and director of local care, NHS NW London
    - Michelle Scaife, programme delivery manager, last phase of life (adults) and London's Universal Care Plan (UCP), NHS NW London.

We would firstly like to thank the members of the model of care working group who met thirty-eight times. Their time, energy, insights, ideas and challenges have contributed to the recommended model of care detailed in this document.

We have received a tremendous amount of feedback and we would like to thank everyone who has taken the time to contribute and share the good and bad experiences of care that they and their loved ones received.

This has been done through the case studies, where people shared their own personal journeys, the people who have attended our various engagement events and our partners whose positive response to the review has been very welcoming.

These stories are deeply personal, but we found that participants wanted to share them because they are passionate about improving the care and support that people receive in NW London.

3. Executive summary

When people are nearing their end-of-life it’s important that they, their families and those important to them can take comfort in the knowledge that there are services and support in place to help them make the last stage of their life as good as possible.

Palliative and end-of-life care is a priority for the NW London Integrated Care System and our health and social care partners across NW London, as well as being a national priority.

In NW London we have some excellent generalist and specialist palliative and end-of-life care services for adults (aged 18 and over), provided by very committed partner organisations, but we know that we need to improve the care we provide in hospitals, community settings (such as hospices and care homes), primary-care settings and patients’ own homes.

We also know that not everyone gets the care and support they deserve in the community. Sadly, in NW London too many people experience less than ideal care as they approach the end-of-their life, with many people spending their last months and weeks in hospital, often dying there, which is not what they want. This is distressing for the patient and their loved ones. It also puts strain on emergency departments and acute hospital beds, diverting NHS resources that could be better used to meet patient needs in more appropriate or effective ways.

What do we mean by home?

Throughout this document we use home to describe the patients usual place of residence: What we mean by home or usual place of residence is a place where you live most of the time and feel comfortable. It's where you have your own space and belongings and normally live most of the time/ spend the majority of your days and nights. It's the place you call home. It could be an apartment, house, hostel or shelter, dedicated care setting (care home, sheltered housing accommodation and mental health facility) where you have a consistent living arrangement at this place.

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-design 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 and will level up the standard of care. 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 those who are 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.

About Susan

Susan is 78 years old and was diagnosed with dementia five years ago. She has a care plan and remains at home with the help of her husband and carer support three times a day from the council. She currently receives general palliative care from her GP, community district nurses and the community mental health team. She is now showing signs of entering the terminal phase of her illness and a review of her care plan by the generalist palliative care teams identifies additional complex needs including pain management and social factors. She is referred to the adult community specialist palliative care team, part of the community specialist palliative care services in NW London to provide specialist support for Susan, her carers and the generalist palliative care team supporting her at home.

Susan is showing signs of entering the terminal phase of her illness with new complex needs identified when reviewing her care plan. She is referred to the adult community specialist palliative care team for specialist support.

Current offer

1. The adult community specialist palliative care team accept the referral but are unable to support Susan, her carers and general care teams at this time due to their current limited capacity and a need to prioritise more complex patients.
2. Susan's husband and the community teams providing generalist palliative care are unable to support her complex needs. And as per her care plan Susan is taken to hospital.
3. Susan is discharged and her care plan updated for increased social care support and adult community specialist palliative care team to ensure all available community support is now being accessed. The community specialist palliative care team visit and provide support for the complex care needs. The care plan includes a care preference for an in-patient hospice unit should her complex needs continue to not be met.
4. Susan, her carers and the community teams continue to struggle, and she is re-admitted to hospital as her deterioration was out of hours, rapid and the in-patient hospice unit was unable to admit due to other patients requiring support as a priority. Unfortunately, she passes away whilst awaiting a care home

Future offer

1. The adult community specialist palliative care team are able to support Susan, her carers and community teams supporting general palliative care, with the complex needs sooner due to their increased hours. Her care plan includes guidance on complex need management.
2. At night when worried there is a 24/7 telephone advice line that Susan and her family can call so they are supported and provided with symptom management advice.
3. The adult community specialist palliative care services regularly review Susan, her carers and community teams changing needs. A Multidisciplinary Team discussion and review of Susan's care plan is arranged by the community palliative care team with Susan and those involved in her care. An enhanced end-of-life care bed is preferred over in-patient hospice unit.
4. Susan, her carers and those involved in her care were involved in the MDT and care plan. Susan is transferred to an enhanced end-of-life bed. Where her long term complex needs can be met.
5. Susan was safe, comfortable and supported and her family were able to be with in her final days.

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 make sure there is fair access to high-quality community-based specialist palliative and end-of-life care for all NW London residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

The specific details of how the services will be organised and provided will be determined in the next phase of the programme, once the new care model is finalised. These details are therefore not included in this document.

The next phase of the programme will be engagement seeking input from the public on the proposed new model of care for community-based specialist palliative care services that is laid out in this document.

Engagement on the model of care will continue throughout the summer and early autumn and will continue as we move forward.

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 proposed new model of care.
- Outline the contents of the proposed new model of care (what is the model of care and not how it will be delivered).
- Seek feedback on the new model of care.

Further details of this engagement, including events and how to respond to this document are available here: www.nwlondonics.nhs.uk/cspc

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

Next steps after this engagement phase – September 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.

When the eventual model of care is agreed and implementation begins, as noted during public engagement, we will work with providers, local stakeholders and our communities to provide clear information to patients, carers, clinicians and the wider public on available services and support. In the meantime, work has already been undertaken to improve available information as part of this new model with the development of a new service directory resource at NW London and local borough level (see: https://hpal.medindex.co.uk/p/t/palliative-care/services).

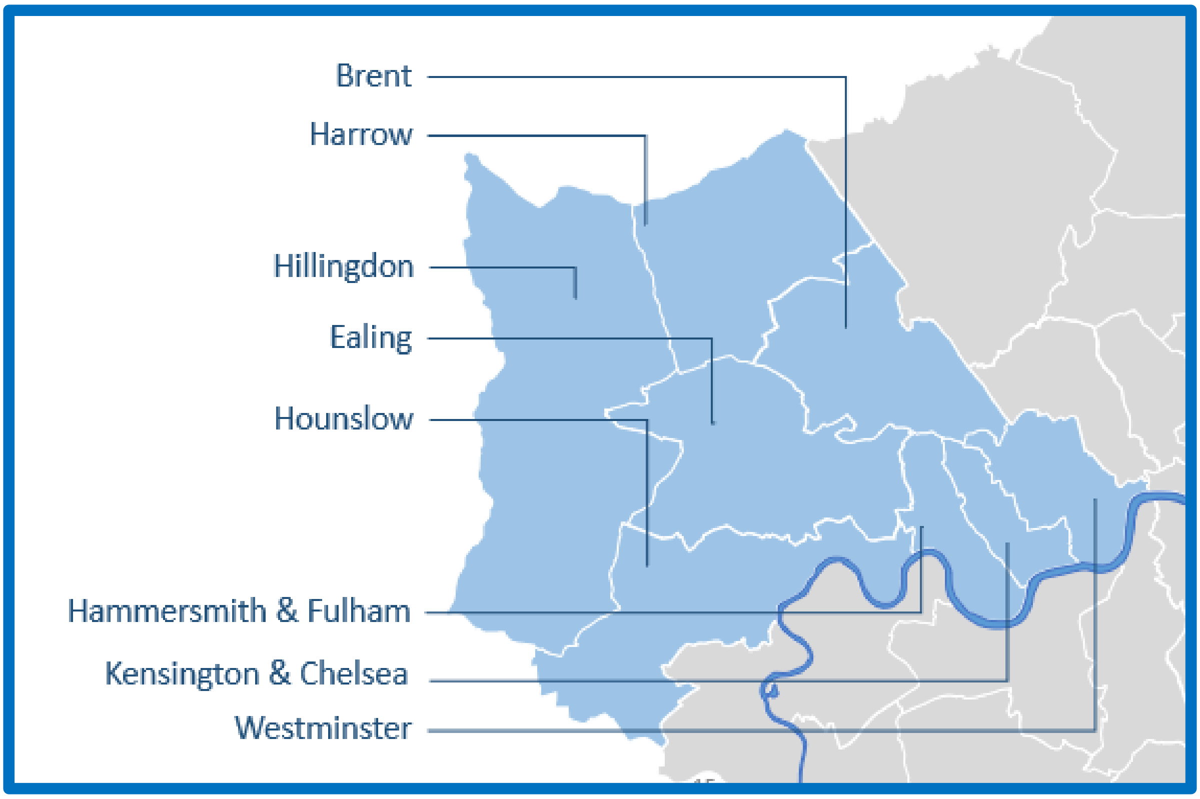
We will continue to work with NW London residents and stakeholders throughout this process and we are immensely grateful for the continued engagement and contributions which are vital to the success of this transformative initiative.

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

4. About us

This improvement programme is being carried out by NHS NW London under the leadership of the NW London Integrated Care System (NW London ICS).

NW London comprises the London Boroughs of Brent, Ealing, Hammersmith and Fulham, Harrow, Hillingdon, Hounslow, Kensington and Chelsea and Westminster.



The NW London ICS consists of all NHS organisations and local authorities in NW London. The following are partners in the NW London ICS:

- NHS North West London (including all NHS boroughs)
- Central and North West London NHS Foundation Trust (CNWL)
- The Hillingdon Hospitals NHS Foundation Trust
- Central London Community Healthcare NHS Trust (CLCH)
- Hounslow and Richmond Community Healthcare NHS Trust
- Imperial College Healthcare NHS Trust
- Royal Brompton and Harefield Hospitals
- Chelsea and Westminster NHS Foundation Trust
- London North West University Healthcare NHS Trust (LNWH)
- London Ambulance Service NHS Trust
- West London NHS Trust
- Brent Council
- Harrow Council
- Hounslow Council
- Ealing Council

- Hammersmith & Fulham Council
- Hillingdon Council
- Royal Borough of Kensington & Chelsea
- Westminster City Council

The NW London ICS serves a population of over 2.1 million people. The purpose of the NW London ICS is to reduce inequalities, increase quality of life and achieve outcomes on a par with the best of global cities. Its priorities are to:

- Improve outcomes in population health and health care.
- Tackle inequalities in outcomes, experience and access.
- Enhance productivity and value for money.
- Help the NHS support broader economic and social development.

To find out more about NHS NW London visit www.nwlondonicb.nhs.uk

To find out more about NW London ICS visit www.nwlondonics.nhs.uk

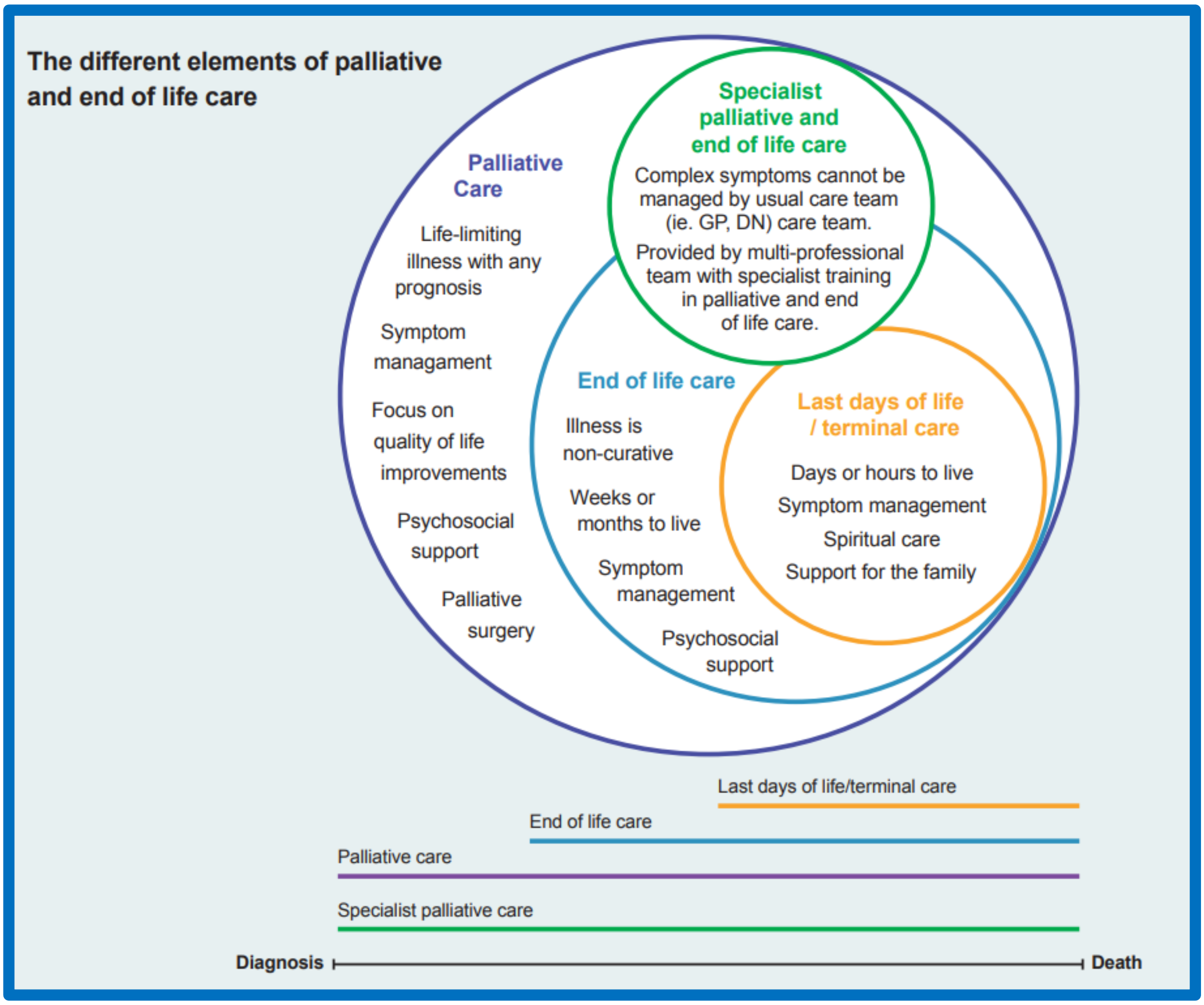
5. What do we mean by palliative and end-of-life care?

Palliative and end-of-life care focuses on enhancing the well-being of individuals with life-limiting illnesses as their health declines and cannot be reversed. This care supports both the person experiencing the illness and their caregivers, including family and friends. The person's wishes are respected to the extent possible, allowing them to pass away with dignity in line with their preferences. The main aim is to provide compassionate and understanding support during this difficult time, prioritising comfort, pain relief, emotional support, and supporting the best possible quality of life throughout this challenging time.

If you have a serious illness and your health is not likely to improve, you may be offered palliative and end-of-life care services. Here's what these terms mean:

- **Palliative care** is a treatment, care and support approach that focuses on improving your quality of life by managing symptoms, relieving pain, and addressing the side effects of your condition. It also provides support for your emotional and practical needs, along with those of your family, friends and caregivers.
- **End-of-life care** is specific type of care for individuals nearing the final stages of their life. It aims to ensure comfort, dignity, and support, managing symptoms and providing emotional and practical assistance.
- **Generalist and specialist palliative care:** Palliative and end-of-life care and support is made up of different levels of care and support, commonly referred to as generalist and specialist palliative and end-of-life care. It is provided by different health care professionals across different settings.
- **Generalist palliative and end-of-life care** is the main foundation level of palliative and end-of-life care support and is provided by healthcare professionals such as a general practitioner (GP), community nurses (including district nurses), care home staff, therapists, domiciliary home care staff (for example care agency staff either arranged by the council, through NHS funded continuing health care or privately) and hospital ward staff who have a general understanding of and training in palliative care. They provide support to patients with serious illnesses or nearing the end-of-life in their home or a medical facility such as a hospital or hospice. For the majority of people with life-limiting or advanced illnesses, this level of care is sufficient throughout their palliative and end-of-life journey, whereas some individuals may require specialised care.
- **Specialist palliative and end-of-life care** is an advanced and specialist level of palliative and end-of-life care provided by expert health care professionals who have received specialised training in this field. Care is provided by a specialist palliative care multidisciplinary team including but not limited to doctor, nurses, therapists, social workers and psychologists. They work with a patient's regular care teams in the community to provide additional support and guidance for complex symptoms and challenges. This type of care is required by individuals with advanced and life-limiting illness that have complex needs and can be medical and social. This care is usually provided in specialist palliative care units, hospices, or at the patient's own home via the specialist multidisciplinary team across

services. This type of specialist care is not required by everybody with palliative care needs and at the end-of-life.



Source: Adapted from diagram produced by Providence Health Care

5.1 What services are provided as part of community-based specialist palliative and end-of-life care?

These services aim to manage symptoms, enhance quality of life, and provide support during the end-of-life process. The goal is to collaborate with patients and their loved ones, tailoring care to meet their specific needs and wishes, and ultimately improve the overall quality of their life and death.

As mentioned in the description for specialist palliative care above, community-based specialist palliative and end-of-life care services are also provided by a specialist multidisciplinary care team providing support across a range of services as follows:

- **Service area 1: Care at home**
    - Adult community specialist palliative care team
    - Hospice at home
    - 24/7 Specialist palliative care telephone advice

- **Service area 2: Community specialist in-patient beds**
  - Enhanced end-of-life care beds
  - Hospice in-patient unit beds
- **Service area 3: Hospice out-patient services (including psychological support and bereavement support services), hospice day care services and well-being services**
  - Hospice out-patient clinics (including (including psychological and bereavement support, and lymphoedema services)
  - Hospice day care services
  - Well-being services

There are other services that may be used by patients receiving community-based specialist palliative care services such as district nursing and rapid response that are outside the scope of this review. However, we have noted the comments given on these services during our engagement and will feedback recommendations to those services, for example: the need for rapid response to work more closely with community-based specialist palliative care services; new models for delivery of rapid response (see 10.1d. Continuing service developments alongside implementation of the proposed new model of care to best support people at home) and the importance of the timely ordering, delivery and collection of medical equipment to patients at home by the community equipment service provider.

Separate to this work, NW London NHS has undertaken a community nursing review, and recommendations of this work include workforce training and recruitment

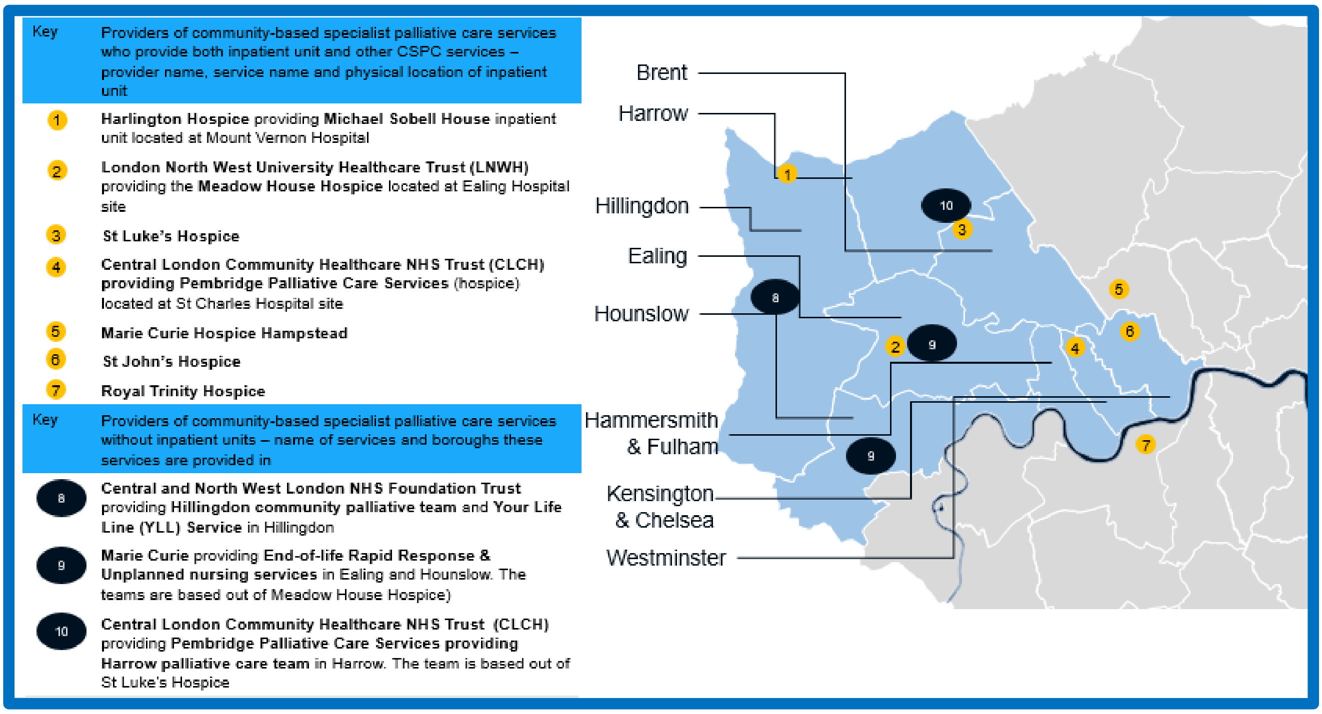
In addition, a number of respondents asked why specialist palliative care services for people children and young people were not included within the model of care. The provider and range of other services involved in supporting children is quite different than for adults, therefore these needs are out of scope of this work. They will be reviewed in future after this model of care is developed and will build on the work to improve adult services.

6. Current community-based specialist palliative care service provision for adults in NW London

There are eight community-based specialist palliative care providers in NW London delivering a wide range of community-based specialist palliative care services and support in each borough.

Three NHS providers – Central London Community Healthcare NHS Trust (CLCH), London North West University Healthcare NHS Trust (LNWUHT) and Central and North West London NHS Foundation Trust (CNWL) – receive their funding from the NHS. The other five providers are independent charitable hospices and receive their funding from a combination of NHS and charitable income.

Map of NW London's commissioned community-based specialist palliative care providers, their services and locations (View a full size map by clicking here).



Key	Providers of community-based specialist palliative care services who provide both inpatient unit and other CSPC services – provider name, service name and physical location of inpatient unit
1	**Harlington Hospice** providing **Michael Sobell House** inpatient unit located at Mount Vernon Hospital
2	**London North West University Healthcare Trust (LNWH)** providing the **Meadow House Hospice** located at Ealing Hospital site
3	**St Luke's Hospice**
4	**Central London Community Healthcare NHS Trust (CLCH) providing Pembridge Palliative Care Services** (hospice) located at St Charles Hospital site
5	**Marie Curie Hospice Hampstead**
6	**St John's Hospice**
7	**Royal Trinity Hospice**
Key	Providers of community-based specialist palliative care services without inpatient units – name of services and boroughs these services are provided in
8	**Central and North West London NHS Foundation Trust** providing **Hillingdon community palliative team** and **Your Life Line (YLL) Service** in Hillingdon
9	**Marie Curie** providing **End-of-life Rapid Response & Unplanned nursing services** in Ealing and Hounslow. The teams are based out of Meadow House Hospice)
10	**Central London Community Healthcare NHS Trust (CLCH) providing Pembridge Palliative Care Services providing Harrow palliative care team** in Harrow. The team is based out of St Luke's Hospice

Area	NW London’s commissioned community-based specialist palliative care service providers by borough
Brent	• St Luke’s Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John’s Hospice • Marie Curie Hospice Hampstead
Ealing	• London North West University Healthcare NHS Trust providing Meadow House Hospice
Hammersmith & Fulham	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John’s Hospice
Harrow	• St Luke’s Hospice • Central London Community Healthcare NHS Trust providing Harrow Adult Community Specialist Palliative Care Nursing Team service
Hillingdon	• Harlington Hospice (including provision of Michael Sobell House in-patient unit at Mount Vernon Hospital) • Central and North West London NHS Foundation Trust providing Hillingdon Adult Community Specialist Palliative Care Nursing Team service and Your Life line 24 service
Hounslow	• London North West University Healthcare NHS Trust providing Meadow House Hospice
Kensington & Chelsea	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John’s Hospice
Westminster	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John’s Hospice

7. How do the proposals address the eight key issues we are seeking to address through this review

While we understand the importance of community-based specialist palliative care working in close partnership with other care sectors, such as acute specialist palliative care and other community services that provide generalist palliative and end-of-life care, to support good community-based specialist palliative care, our programme of work does not involve reviewing the provision of acute specialist palliative care and these other community services.

In late 2021, we set out the reasons we needed to improve and increase the level of community-based specialist palliative care for adults (18+ years) in an Issues Paper and highlighted that it is the most fragile part of the palliative and end-of-life care services in NW London.

We identified eight key issues that needed to be addressed and engaged with local residents and partners to find out what was important to them.

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
1	Respond to future need	• 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. • 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.
2	Address service variation	• 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.
3	Respond to inequalities	• Undertook a travel mapping exercise (travel analysis) to understand impact on communities travelling to 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. • 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. • 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.
4	Integrated delivery	• 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.
5	Responding to feedback and engagement	• Involved patients, carers, clinicians and members of the public in co-designing the model of care, ensuring the voice of local residents is truly reflected in service design • 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.
6	Align with policy & best practice guidance	• Reviewed best practice and national guidance and integrated these within model of care working group discussions to shape and develop each core service offer • Actively engaged with other organisations, areas and systems who have been implementing new models to inform our local work.
7	Financially sustainable	• 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.
8	Recruitment and retention	• 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.

7.1 Issue one: Responding to future need and meeting the palliative care needs of NW London's changing population

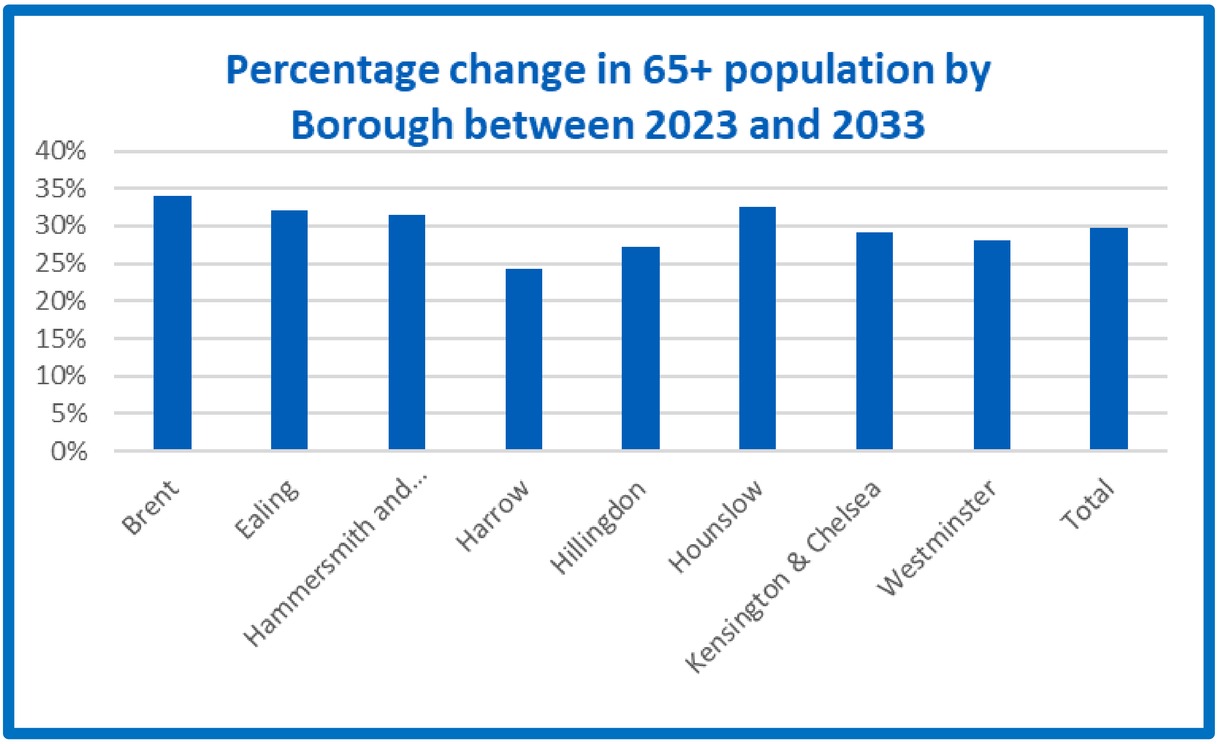
We committed to undertaking further demand modelling and population projections for a ten-year period to support future services modelling (see the full analysis).

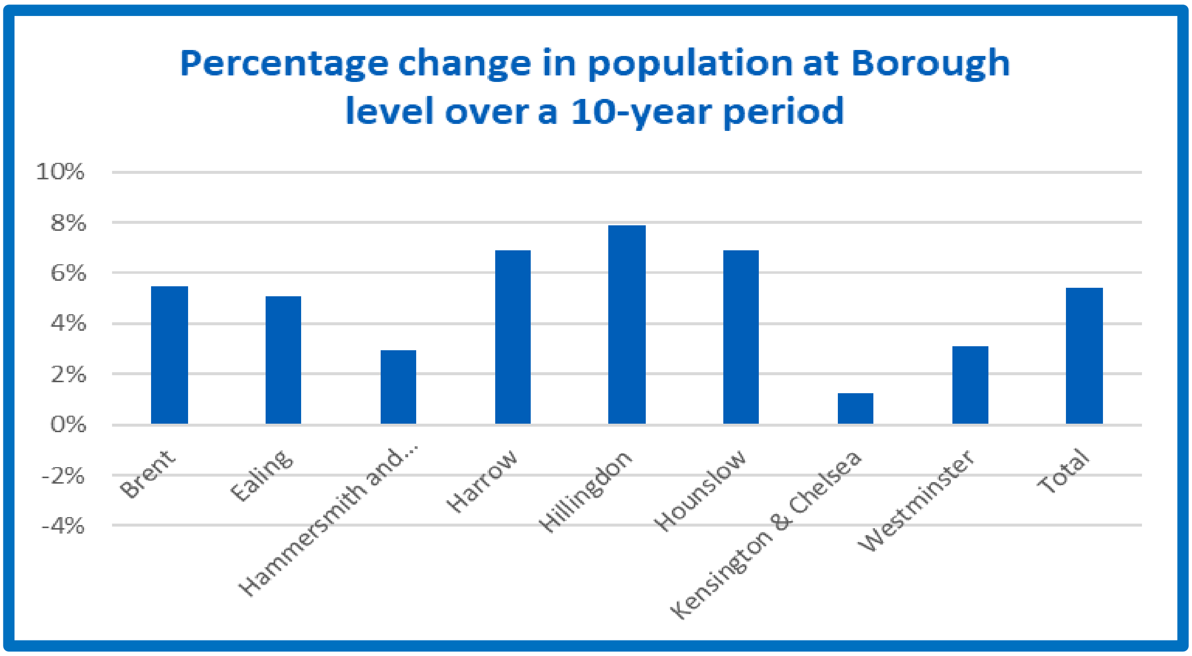
The outcomes of this work show that we can expect growth in hospice and specialist palliative care service in-patient unit beds use to be in-line with the growth in the overall number of deaths in the NW London population over time. This is the result of an ageing population, population growth and a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

The model of care group looked 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.

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.





During this time, the population size in NW London 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[1]. In NW London, the 65+ population is expected to grow by 30% over the same ten-year timeframe. This is a much faster rate than the 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 the 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 an ageing population and population growth and is based on the pattern of change modelled nationally[2].

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[1] Monthly figures on deaths registered in England and Wales, ONS, August 2022

[2] ONS Deaths Data

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?

According to national data (see table below), the current statistics for NW London show that approximately half of people (48%) pass away in hospitals, while 28% die at home. Additionally, 12% of people die in care homes, and 5% pass away in hospices. These figures are consistent with the data observed in London as a whole. However, it is important to note that we have not yet reached the national average, particularly concerning deaths in care homes and homes.

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)[3] suggested 81% of people wished to die at home. 8% of people stated a preference for a hospice, 7% for a care home and only 3% for a hospital.

It should be noted that care homes are also for many people ‘their home’ although this might not be considered when expressing their wishes earlier in their end-of-life journey.

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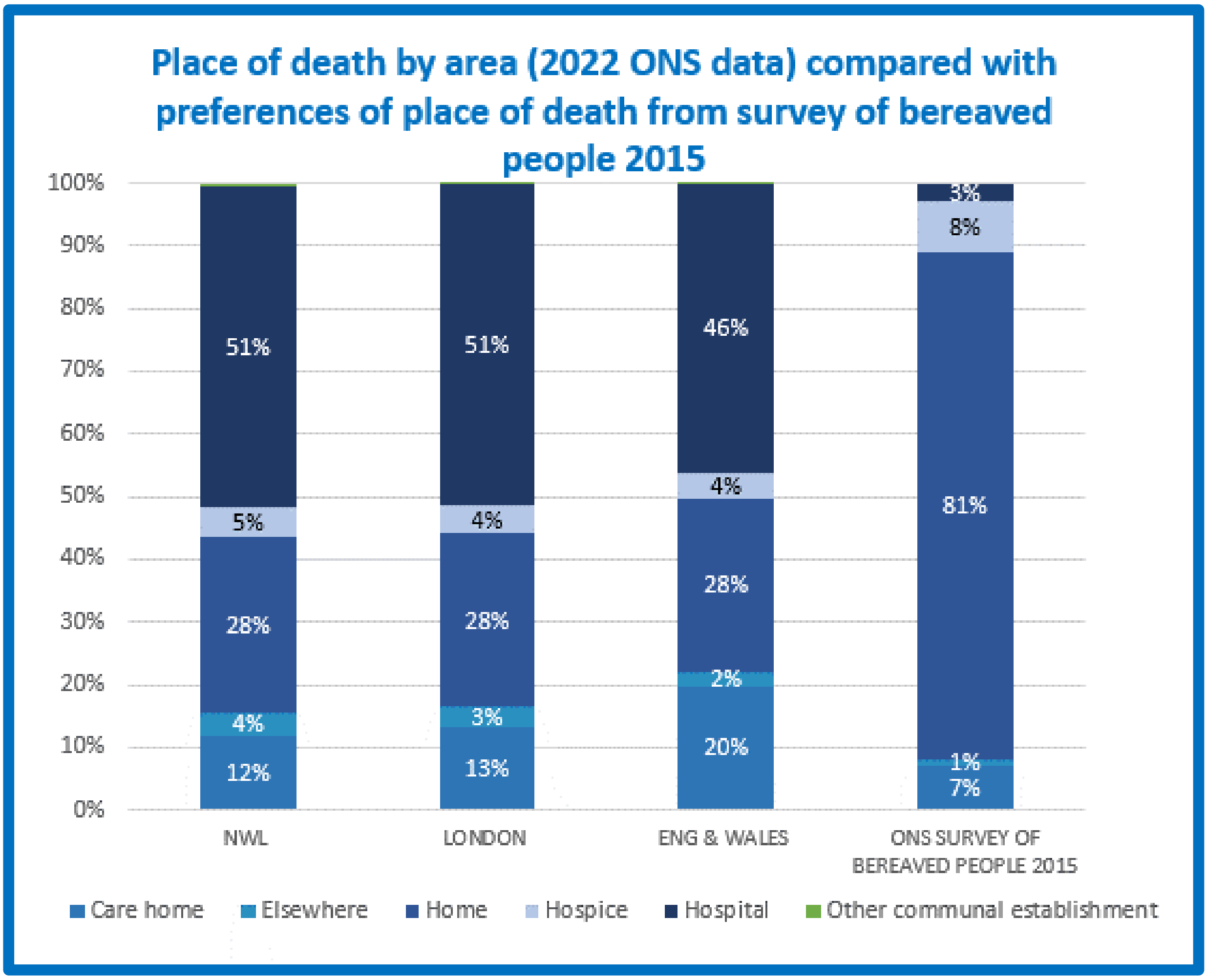
[3] National Survey of Bereaved People (VOICES - Views of Informal Carers - Evaluation of Services), England, 2015

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



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

7.2 Issue two: Addressing service variation, improving access to care for all and making sure that everyone receives the same level of care, regardless of where they live

Making sure all NW London residents receive the same high level of core services

We identified at the start of the review that not everyone in NW London receives the same level of care, regardless of where they live. We have done mapping of existing services to identify gaps in provision and variation, which have been used to support the recommendations for the service common core offers and changes proposed in the new model of care. At the moment there are differences in the quality and level of community-based specialist care that patients, families and carers across NW London receive. This means that depending on where a patient lives, they and their family and carers may not get the support they need, and may not be able to have their wishes supported at the end of their life. We committed to do all we can to make sure this is not the case.

This was reinforced during our engagement where we received feedback on areas of concern where we were able to take immediate action to level up care. Not all these relate to community-based specialist palliative care but they highlight how the work we are carrying out is able to influence care across the whole palliative care pathway in a positive way. There were also some areas identified that will be addressed through implementation of the recommended model of care.

Feedback	Action taken
Align GPs more closely with individual care homes and develop enhanced care service for care home residents. This needs to include the development of personalised care plans to support their care needs and expressed wishes and involve relevant health professionals and the families and carers in these care planning conversations in as much as possible.	As part of the Primary Care Network (PCN) Direct Enhanced Service (DES) all care homes in NW London have a named GP and where possible are aligned to a single PCN. A NW London wide common core standard has been agreed that will provide enhanced support to care homes and cover the provision of multidisciplinary team (MDT) working and personalised care and support planning. This includes advance care planning and use of the Universal Care Plan. Implementation is being done at a local level in each of the NW London boroughs
Increased access to end-of-life and anticipatory medication in the community. Community Pharmacists should be included in the engagement and review process to understand the issue of availability and timely access to end-of-life medication for patients, families and carers and clinicians in the community.	Not all boroughs had the same level of in and out of hours' access to end-of-life care and anticipatory medication. The gap in West London, Central London and Hammersmith & Fulham boroughs was closed by commissioning an equivalent service, meaning that since the pandemic all NW London residents have equal access to these medications 24-hours a day. The NW London Medicines Management Team have put in place services to make sure there is ongoing 24-hour access to end-of-life and anticipatory medications in the community.

	NW London implemented the Pan-London Symptom Control Administration (MAAR) Chart, This MAAR chart supports safe administration of complex injectable regimens. NW London also collaboratively developed with key stakeholders a NW London wide resource to support primary care with palliative and end-of-life care symptom management, accessing anticipatory medications, accessing community based specialist palliative care for adults and use of the MAAR chart
Access to 24/7 end-of-life care advice and support for patients, families, carers and clinicians, which includes a single point of access and co-ordination service. This is of particular importance during the out of hours period between 5pm and 8am when the patient may be experiencing a lot of pain and the family and carer may not be able to contact the usual care team or know which services to contact for support.	All of the hospices that provide services in NW London now provide 24/7 nurse-led advice lines that have 24/7 palliative care consultant support. A further gap was identified for the Harrow Community Specialist Palliative Care team who do not have seven day working and visiting available. This will need to be addressed through the implementation of the recommended new model of care.
Having hospice in-patient services locally is very important, particularly for residents where the spouse, carer and family of the patient requiring hospice in-patient care is elderly or has family and work commitments and are negatively impacted by increased travelling time. Consideration should be given to re-opening the Pembridge in-patient service as part of the service review.	The model of care working group is recommending that there is an increase in the range and number of specialist in-patient bed care options available by introducing enhanced end-of-life care beds, for people with less complex specialist palliative care needs who still require in-patient care. This will be on top of the existing hospice in-patient beds that we currently have.
Not enough support available or not a consistent offer of bereavement support (pre and post death) available to patients, families and carers. Feedback included whether this could be reviewed as part of the latest programme of work to understand	Bereavement care and support really came to the fore as a gap nationally, regionally and locally during the Covid-pandemic. Through the community-based specialist palliative care review programme we have scoped current provision and gaps for NW London and

current provision and what more could be done to improve the offer.	considered how to improve these services as part of the new model of care development work. See section 10.3c Service area 3 Hospice out-patient services, hospice day care services, and well-being services (including psychological and bereavement support) for further details.

We extensively mapped existing services to identify gaps in provision and variation, which have been used to support the recommendations for the service common core offers and changes proposed in the new model of care.

The recommended model of care seeks to improve the care offered so that everyone in NW London irrespective of where they live will receive the same high level of core services at the end of an agreed implementation period.

7.3 Issue three: Reducing health inequalities and social exclusion

A goal of the review was to mitigate health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.

Health inequalities are much broader than this work as acknowledged in the NW London health inequalities strategy.

NW London health inequalities strategy

Health inequality is a major problem for NW London. People in less well-off areas are more likely to have a disability or be living with a long term condition. People from a Black, Asian or other ethnic minority background are more likely to live in less affluent areas, as are people who are less well educated or working in lower paid jobs. People from these populations can find it harder to access healthcare, receive a high quality service and get a good health outcome. The Covid-19 pandemic has both increased health inequality in NW London and shone a spotlight on it. Over the next five years, we're determined to transform care to ensure greater equality of access, experience and outcomes. This will include tackling difficult issues like structural racism and poverty[4].

The NW London commitment

Our commitment starting from now and over the next five years, is for NW London to rapidly progress towards a place full of healthy communities, where

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[4] NW London ICS: Tackling health inequality across NW London

we can – as individuals, families, and friends – all contribute to (and benefit from) inclusive economies, lead flourishing lives, and maximise our wellbeing and independence.

In support of this wide NW London commitment we are recommending the introduction of a range of initiatives including the introduction of a cultural competency training programme, culturally sensitive care planning and asking all providers to commit to an outreach programme.

More detail of our plans to reduce health inequalities can be found in section 11.2 the key enablers that will help us deliver the new model of care.

7.4 Issue four: Integrated delivery of care and making care more joined up and easier to navigate

We committed at the start of this work to make it easier for people to access services, particularly across our more diverse communities. We acknowledged that some of our services are not joined up and do not work well together, and we need to change this. This was also a constant theme coming through our engagement.

We are seeking to address this through the model of care with improved access and extended opening times including the 24/7 advice line which will help known and unknown patients and families. More detail of our plans to improve access and increasing the reach of the services can be found in section 11 the key enablers that will help us to deliver the new model of care.

The review programme has also brought together our charitable and NHS providers of care and they have been working collectively to agree the model of care and discuss how they can better work together. At a very basic level our providers continue to meet weekly sharing issues and solutions together, avoiding reinventing the wheel and providing mutual support on how to best improve care. This basic joint working is unusual across the country and provides a bedrock for integration and transparency on challenges.

More needs to be done to integrate our acute specialist and generalist palliative care services but this is acknowledged and we have a number of actions which support this. The implementation of the Universal Care Plan is key as it supports good information sharing across organisations reducing the need for patients to repeat their stories.

7.5 Issue five: Responding to feedback and engagement and building on the valuable learning and feedback received from previous reviews of palliative and end-of-life care services and ongoing engagement

> “We would like to thank everyone who has taken the time to read through the Issues Paper and for attending one of our events, completing the survey or giving us feedback by other means. The feedback received has been both personal and will provide valuable insights on how we get end-of-life and palliative care services right for all residents.”
>
> **Robyn Doran, senior responsible officer, NW London community-based specialist palliative care review programme**

Following publication of the Issues Paper in November 2021, we spent considerable time listening to the views of our communities to understand what was important to them in receiving community-based specialist palliative care.

We arranged a series of ten events and webinars at which we presented and took questions from members of the public and clinical staff, capturing the key issues raised and ensuring these fed back into the work to develop the model of care.

Following these meetings we were referred to or approached a number of voluntary and community organisations and representatives for further one-to one interviews and discussions aimed at gaining an in-depth understanding of the issues and challenges for specific (often hard-to-reach) groups of people.

This in turn helped us identify some key groups for whom we lacked information or input and needed to link-in with experts both locally and nationally to better understand what was important to these groups in terms of end-of-life and specialist palliative care. This led to us conducting desk research, reviewing the information published by health providers, charities and journals, and producing three literature reviews covering learning disabilities, people living with homelessness and younger adults (approximately 18-45 years old), which we published and used as evidence in the review.

We attended, and continue to attend, Health and Wellbeing Boards, Scrutiny Committees and Health Committee sessions across the NW London boroughs to brief elected members and stakeholders on our work and answer their questions on the development of the model of care.

In addition to all of these direct meetings and conversations, we developed a number of online surveys through which local residents and health and social care professionals could give their views. Open-ended questions were also included to give respondents the opportunity to express their opinions in their own words. We received feedback from 188 respondents across six surveys, along with two formal written submissions.

During this engagement work, we met or spoke to some local residents who were kind enough to share their stories so we could use them as case studies to illustrate both the good experiences and the challenges that people face when using community-based specialist palliative care services. This led to the development of nine patient stories that highlighted problems that need to be addressed and how the model of care will need to support improvements.

The overall feedback was published in the Engagement Outcome Report and we used these valuable insights from members of the public to feed directly into the development of a new model of care.

We have also taken a number of actions to address issues and make improvements whilst our work on the new model of care is ongoing. These are covered in section 7.2 and within the Engagement Outcome report (pages11-14) and include, for example, increasing access to end-of-life and anticipatory medication in the community and access to 24/7 end-of-care advice.

From the extensive engagement undertaken, we collected a wealth of feedback that described 'what' services needed to provide from the perspective of service users and families and also 'how' they are cared for. The substantial feedback can be summarised into the following themes.

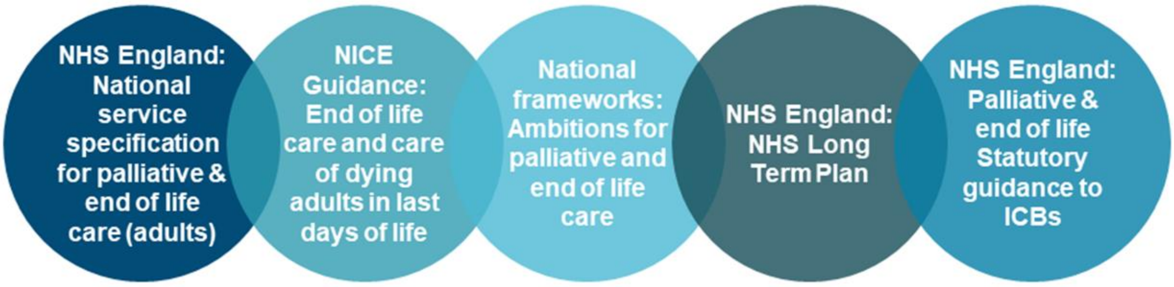
Engagement Themes		Summary Feedback
1	**Best possible care**	High quality care delivered in the optimal place, supported by evidence-based pathways
2	**Care tailored to my needs**	Care personalised to me, my preferences and needs. An approach to care planning that factors in my individual requirements, considering my conditions. For example, dementia, my ethnicity or sexual orientation.
3	**Providing connected care**	Care providers working together so care feels integrated and services are easy for me and my family to navigate and access.
4	**Staying informed**	I know where to find information regarding specialist palliative care services across NW London. I know who I can speak to find help and support.
5	**Creating professional culture and behaviours that exhibit sensitivity and compassion**	All staff exude compassion in their interactions with me, my family and those important to me. They show an understanding of how my faith and culture might lead to differences in the help I need.

6	**Supporting carers & families through end-of-life and beyond**	Bereavement, respite and emotional support.

7.6 Issue six: Making sure our services are aligned to nationally recommended standards and evidence

Periodically reviewing local services to check they are responding to the latest evidence and best practice guidelines helps us to make sure we continue to improve care for residents.

In the case of improving community-based specialist palliative care, we are guided by a core set of documents that nationally describe what good end-of-life care looks like. These are outlined below. For a more complete set of guidance we have used, please see Appendix B.



7.7 Issue seven: How financially sustainable is community-based specialist palliative care now and in future?

To cope with the increasing financial challenge, the NHS and social care is facing and the effect this has on community-based specialist palliative care we need to make sure the model of care and the service options that are developed are affordable and sustainable for the long-term.

Nationally, NHS spending has not been cut, but we have to acknowledge the financial constraints that local authorities are operating under and the knock on effect it has. NHS spending has risen slightly above inflation every year since 2010. But the costs of providing care are rising much more quickly than that, due to innovative but costly new technologies and rapidly increasing demand from a rising and ageing population. This has been further accelerated by the Covid-19 pandemic and has worsened since then.

The amount spent across NW London on community-based specialist palliative care in 2021/2022 was around £18 million. Whilst the amount we spend is not likely to fall, we cannot be sure we will be able to get an increase in funding as we move forward. We must take this into account when developing services if we are to develop equitable and sustainable services for the future. We also need to take into account that if we delivered everything that everyone wanted our services would not be affordable. In addition, we have found:

- The majority of funding for hospice comes from donations and fundraising which means they are at risk if a crisis such as Covid-19 leads to a fall in this funding stream
- There is considerable variation in NW London's community-based specialist palliative care contracts and the amount the NHS pays. Work is being carried out to look at look at how we can standardise payments
- Moving forward, affordability will be one of the criteria in accessing which service options are deliverable.

The non-NHS hospice sector is reliant on a combination of NHS and non-NHS funding, with the latter requiring substantial fund raising by the charitable hospices. During the pandemic the amount the hospices were able to fundraise was substantially reduced. However, national NHS support was a welcome means of making sure the hospice sector was able to continue critical delivery. Recovery after the pandemic, coupled with pressures from increased cost-of-living and the NHS pay award, mean the hospice sector faces further unprecedented financial challenges. It is in the best interest of NW London ICS and NW London residents to avoid any organisation becoming unviable. Therefore, in future all funding plans will need to take into account the need to build-in this resilience and the partnership we have as co-funders of services.

7.8 Issue eight: Recruiting and retaining a skilled workforce now and for the future

At the beginning of the review we acknowledged the difficulty all organisations were having in recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services. In the period since then this has worsened and there is a national shortage of staff in all areas, not just palliative care.

The new model of care has to address different ways of working, focusing on how we support our staff regardless of what organisation they work for. We also need to make best use of our most hard to find team members. To do this we need to think about how we can plan for workforce growth, but in the interim focus on productive ways of working. Our providers are really good at sharing their learning on what has worked well. For example, how we use support roles so our most skilled roles are not doing the 'chasing' that other team members can help with, and how we balance out home based care and out-patient care to enable efficiencies in the way we care for patients, whilst at the same time maintaining the quality of care.

Notwithstanding this, the developing NW London Health and Care Strategy has workforce development as a key priority and it is a key priority for the programme. Being able to recruit and retain staff is key to delivering the model of care and more of our plans to build a skilled workforce are laid out in Section 11.1 Workforce development to address need for pipeline of skilled workforce into the future.

8. The NW London adult community-based specialist palliative care new model of care working group (new model of care working group)

Following the launch of the Issues paper in November 2021 and on the back of our engagement about the issues, the new model of care working group was set up by the NW London ICS to develop a model of care to make sure:

- The themes raised through our engagement were addressed
- All NW London residents are able to access the services, if needed
- That high quality community-based specialist palliative care is delivered equitably and sustainably across NW London.

The model of care does not address how we will configure services. What is described is the level of care that all residents should expect to receive.

Click here to view the minutes of the model of care working group

Membership of the group, which met thirty-eight times over a year, consisted of local residents, clinicians and other palliative and end-of-life care stakeholders, and more details can be seen in the acknowledgement section of this document.

The objective of the group was to develop a new model of care for community-based specialist palliative care for adults that addressed "what good looks like", including developing the underpinning design principles and high level cross-cutting enablers to support implementation and delivery of the new model.

This involved using engagement feedback, national guidance and supporting documentation, and key reports to agree a set of key definitions standards and a common core offer of services. This will later be built into a single service specification for NW London once the new model of care has been agreed.

During meetings the group looked in detail at the different aspects of community-based specialist palliative care drawing on:

- The national service specification for adult palliative and end-of-life care
- The previous NW London palliative care review programme work from 2019/2020
- The qualitative and quantitative feedback from residents and healthcare professionals obtained through our extensive engagement
- Population projections
- Demand modelling
- Travel mapping.

The new model of care working group have collectively agreed and recommended a set of core services with a common core offer for community-based specialist palliative care provision that NW London residents can expect to receive regardless of the borough they live in. Some of these services are already available to all boroughs, while others are new additions for some boroughs and will raise and level-up the standard of care where these services do not exist or vary a lot.

They have also agreed five cross cutting enablers to support successful implementation and delivery. These are detailed in the following sections of this document.

The model of care has also been agreed by the NW London community-based specialist palliative care steering group.

9. Introducing the proposed NW London adult community-based specialist palliative care new model of care

The recommended model of care has three key service areas, each providing different services to meet the patient needs. Within these three service areas are seven core service lines For NW London the eight community-based specialist palliative care providers we commission will deliver a comprehensive range of services for all NW London residents.

9.1 Service area 1: Care at home

In this service area, the focus is on delivering compassionate and specialised care to patients in the comfort of their homes. The primary aim is to maximise the quality of life and comfort of the patient and support their wish to remain at home or usual place of residence in the community during their palliative and end-of-life journey.

To make sure the patient receives the highest quality of care, a dedicated adult community specialist palliative care team is at the forefront of care, providing personalised and comprehensive support. This team is well-equipped to handle various aspects of care, including pain relief, symptom management, and emotional support, tailoring their approach to meet the unique needs and preferences of each patient.

The specialist nurses in this team play a key role in co-ordinating the patient's care with the other services and health professionals involved in the patient's care. They also:

- Support carers by providing information on their needs, education and practical support.
- Provide training and education for care home staff and wider generalist palliative care health professionals.

The hospice at home service, a vital component of this service area, offers direct hospice care to patients in their home or usual place of residences. This service provides comfort for patients and essential support to caregivers, acknowledging the significant role they play in the patient's palliative and end-of-life care journey.

The service area also includes 24/7 specialist palliative care telephone advice for patients (both known to services and the wider community with palliative care needs), their family, carers and clinicians in the community.

It gives continuous access to expert medical guidance and support to navigate services for patients and their families. The round the clock availability of this support helps to improve the wellbeing and care of patients with the knowledge that they have that support easily accessible.

It also minimises the need for unnecessary hospital admissions, as patients can receive timely advice, particularly during out-of-hour periods.

By prioritising home-based care, this service area aims to improve patient outcomes by enhancing their overall well-being at home and reducing the stress associated with unnecessary hospital admissions. It helps to make sure that patients receive the right care at the right time in the comforts of their familiar surroundings.

For further detail see section 10.1

9.2 Service area 2: Community specialist in-patient bed care

For this service area there are two types of beds available to meet the diverse needs of patients with specialist palliative care needs and approaching the end-of-life.

Firstly, the enhanced end-of-life care beds which cater to a specific group of patients who have some specialist palliative and end-of-life care needs but may not be eligible for hospice in-patient unit beds as their needs are not complex enough to require this level of support. These patients may not be able to stay at home due to various medical and social reasons. They may also prefer not to stay at home or be in a hospital setting, or need to be in hospital. These enhanced end-of-life care beds offer a wider range of care options for this group of patients. The main goal is to address the unmet needs of these patients and provide them with the best possible care and support during their end-of-life journey.

Secondly, there are hospice in-patient unit beds specifically designed to support more complex patients. These patients might require a short admission to a hospice in-patient unit bed to receive specialised and intensive support. They may have challenging symptoms that need stabilisation or may need expert assistance during a complex death process. The hospice in-patient unit beds offer 24-hour intensive medical support to provide the necessary care for the needs of these types of patient.

By offering both types of beds, patients have improved choices for in-patient bed care in the community that better suits their individual requirements and preferences. The focus is on making sure that each patient receives the right level of care at the right time during their end-of-life journey when they need in-patient bed care.

For further detail see section 10.2

9.3 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)

Community-based specialist palliative care recognises the importance of addressing the physical, emotional, and spiritual well-being of patients. This service area is dedicated to providing out-patient and well-being services to patients and their families, caregivers and those important to them. It offers a comprehensive range of support for individuals facing life-limiting illnesses.

At the heart of these services are a multidisciplinary team of professionals who are specialists in palliative and end-of-life care who collaborate to complete holistic assessments and develop personalised care plans and treatment interventions tailored to each patient's unique needs and circumstances (for example pain management, diagnostics, rehabilitation). They provide support via multidisciplinary out-patient clinics which can be one–to-one or group sessions.

For patients with lymphatic system issues (cancer and non-cancer related), the service area also provides specialised lymphoedema services as part of out-patient clinics. The aim is to make sure that they receive expert care and management for their lymphoedema condition.

Recognising the significant emotional and psychological impact that life-limiting illnesses can have on both patients and their loved ones, the service area offers crucial psychological support. This support entails counselling and therapy services designed to address the emotional and psychological needs of patients and their loved ones as they navigate the challenges that come with the illness.

Furthermore, the service area extends its support beyond the patients’ lifetimes. Following the death of a patient, their loved ones can access bereavement support services, which aim to assist them in coping with grief and loss. These services include one-to-one grief counselling and group therapy, providing a safe space for individuals to process their feelings and find support among others who have experienced similar losses.

In addition to traditional medical approaches, the service area recognises the importance of holistic well-being as part of well-being services, with hospices offering a range of day care services (for example peer support groups led by volunteers) and complimentary therapies (for example massage, art therapy, music therapy, relaxation therapies) to promote overall wellness and complement conventional medical treatments. This further enhances the quality of care and support they provide to patients and their families. These therapies are not routinely funded by the NHS as national guidance describes this type of care and support as “enhanced” non-core clinical services not funded by the NHS.

The model of care working group recognised the importance of the hospices continuing to provide these day care and complementary services as part of their well-being service offer via chartable funding avenues. They also recommended that we include improved bereavement and psychological support as a core service element of the well-being offer in the new model of care.

For further detail see section 10.3

9.4 Summary of the core services within the three service areas

The table below summarises the core services that make up each of the three service areas in the model, the current levels of service available in NW London and explains where the changes and levelling-up of services will take place as part of the recommended new model of care.

	Core Service	Current service levels	Recommendations for new model
Service area 1: Care at home			
1a	Adult community specialist palliative care team	Available in all boroughs 9am to 5pm, but with some services operating seven days and others only five days (for borough of Harrow)	Increased service hours to 8am to 8pm, and all services to be seven days
1b	Hospice at Home	Available in five boroughs, but not Ealing, Hammersmith and Fulham and Hounslow, and not all providing consistent offer of up to 24-hours of care if needed	Extended service coverage to all boroughs and increased consistent service offer of up to 24-hours
1c	24/7 specialist palliative care telephone advice	Available in all boroughs but not all services consistently supporting patients who are known and unknown to their services	Extended service offer consistently available to unknown patients in addition to known patients
Service area 2: Community specialist in-patient beds			
2a	Enhanced end-of-life care beds	Available only for borough of Hillingdon	Extended offer to remaining seven boroughs who currently don’t have this provision
2b	Hospice in-patient unit bed care	Available for all boroughs, but services currently do not consistently support 7-day admissions for planned and unplanned (emergency admissions) or have consistent admission criteria	Consistent seven day admissions for both planned and unplanned admissions, along with consistent admissions criteria across all providers of these hospice inpatient unit services

Service area 3: Hospice out-patient services, hospice day care services and well-being services (including psychological and bereavement support services)			
3a	Hospice out-patient services including out-patient clinics with the hospice multidisciplinary team (MDT) and Lymphoedema services	Out-patient clinics are available for all boroughs but there is a gap for the boroughs of Ealing and Hounslow for medical and nursing outpatient clinics Lymphoedema services are available to all boroughs but this is not a consistent offer, whilst the borough of Harrow only has cancer lymphoedema services available (no non-cancer lymphoedema services available)	Common offer for hospice out-patient clinics with extended non-cancer lymphoedema service coverage for borough of Harrow
3b	Day care services (including family and carer support services) Well-being services (including psychological and bereavement support services for patient and their family, carers and friends	All providers offer a wide range of day care services which are charitably funded All providers offer a comprehensive range of well-being initiatives and access to complimentary therapies (via charitable hospices) All providers offer or support access to psychological and bereavement but the full complement of this type of support is only available in the borough of Hillingdon, who offer access to specialist psychological support services beyond the hospice	A core level of service and clearer robust pathway for access to appropriate, psychological and bereavement support services in particular.

Together, these core services will work in partnership to deliver the new model of care across NW London. By offering a single common and consistent level of high-quality care, we will be levelling up service delivery and making sure that everyone in the community has access to the same standard of support.

The way in which people will be cared for in our future model includes a greater degree of personalised care delivered in a culturally and faith sensitive manner, with improved coordination among providers and the various services.

We recognise the value of each existing service and the care provided. Our proposal is to retain all of them in the future, but require them to deliver care to an agreed standard that has been identified by the model of care working group in accordance with national policy, best practice and our engagement outcomes.

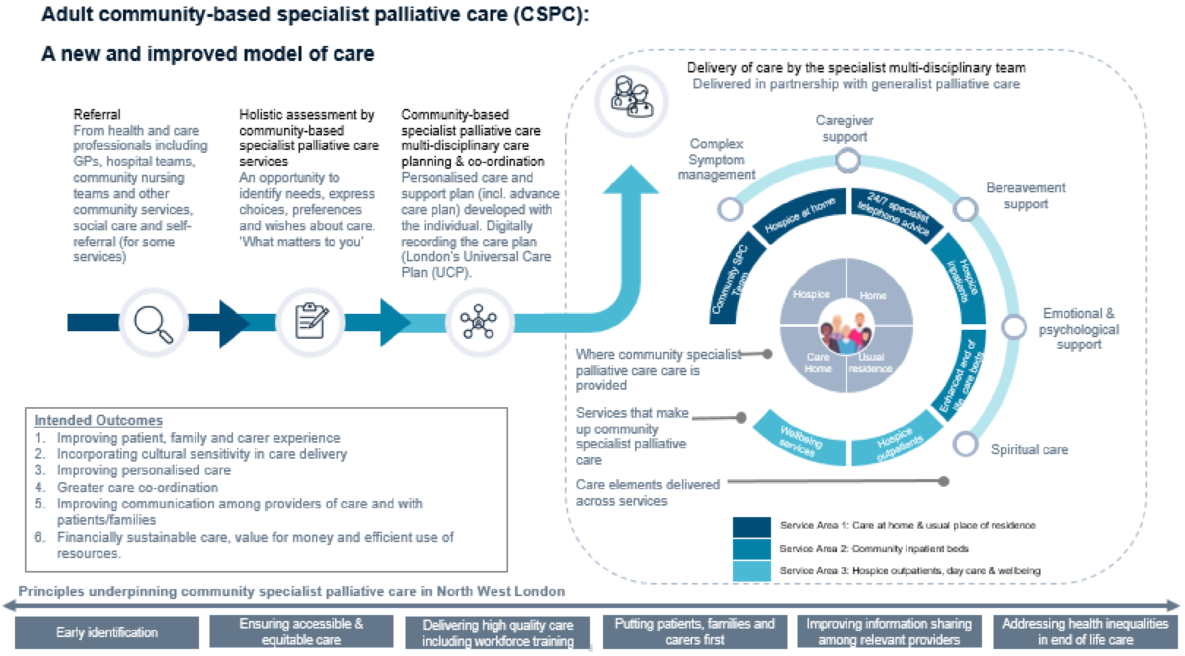
We also propose increasing the overall number of community specialist in-patient beds available to support patients by adding a new type of bed called "enhanced end-of-life care beds" to address a specific identified gap in our provision and meet more of our residents' needs.

Individual boroughs and providers will still have the flexibility to develop additional services to meet any local needs to safeguard against any service inequity for local communities. We want to foster innovation and spread good practice to wider populations as these are evaluated. However, these services are out of the scope of the model of care at this time.

We have also established a set of principles that underpin the future model, and will apply no matter what care offer you receive, or which setting you receive your care in. A summary diagram of the model of care can be found in section below.

9.5 How the new model of care works?

(click here to view a larger view of the diagram)



Intended Outcomes

1. Improving patient, family and carer experience
2. Incorporating cultural sensitivity in care delivery
3. Improving personalised care
4. Greater care co-ordination
5. Improving communication among providers of care and with patients/families
6. Financially sustainable care, value for money and efficient use of resources.

The person with a life-limiting illness's journey starts with health care professionals (for example GP, district nurse) involved in the patient's care identifying patients who would benefit from the care and support that community-based specialist palliative care can provide. The patient is then referred for assessment by a health professional to see if they are eligible to make use of community-based specialist palliative care services. Residents also have the option to initiate a self-referral, but this will require additional clinical information to be provided from a healthcare professional involved in their care to support the referral process.

The person and their family, carers and those important to them go through a comprehensive assessment and care planning process which will identify need and lead to the delivery of a personalised offer of community-based specialist palliative care. Advanced care planning will also take into account their future care preferences and services will support the patient in as much as possible to have those preferences adhered to. These steps and processes for providing the most appropriate care at the right time are also known as the care pathway. They go beyond palliative and end-of-life care for the patient, and also include emotional, practical and bereavement support for families and caregivers.

Patients accepted by the services can expect to receive a package of tailored and coordinated care delivered in their home.

In situations where patients are not accepted into the community-based specialist palliative care services, the relevant teams will assist by providing guidance and information to the referrer and patient. They will signpost the referrer or the patient to the most appropriate service available, making sure that patients receive the support they need. Even if it is outside of the immediate scope of care for community-based specialist palliative care services.

The care that patients, as well as their families and carers, receive depends on individual need and might include symptom management (including pain management, psychological symptom support for example) or bereavement support.

People facing advanced illnesses and terminal prognoses often experience changing needs over time. They may require the support of a number of the community-based specialist palliative care core services to meet their unique needs. To make sure they continue to receive the support they need, patients will be regularly assessed by a team of multidisciplinary experts working in close collaboration with the patient's GP, other community services and care professionals involved in the patient's care.

This assessment will include reviewing the care plans of patients and the needs of their caregivers, families, and other important individuals in their lives. By continuously assessing and adjusting the care provided as needed, the new model of care can effectively adapt to the evolving needs and preferences of each patient at the right time and most effectively.

This will also be achieved through the services working more closely together and in closer partnership with other community services providing generalist palliative care and social care, for example district nurses and primary care, with frequent joint review of patients' needs and preferences.

Additionally, there will be an increasing use of technology within services to help deliver care. For example, we will expand the use of the London's Universal Care Plan (UCP) across our care sectors and settings. This is a digital personalised care plan which is used to make sure that the patients' wishes are recorded and shared in real time across the health and care system and that health and social care professionals can access whilst providing care. Other examples include virtual consultation and scheduling tools, which help make best use of the workforce who are travelling in the community to deliver services to patients.

The aim is to make sure the right level of support is provided at each stage of the patient's journey through palliative care and to the end of their life. For example, a patient may start off being supported by the adult community specialist palliative care team, but as their condition or illness develops may also require the support of the hospice at home team. They may also require a short-term admission to a bed in a hospice in-patient unit if their illness, symptoms or social circumstances become too challenging for the care teams to manage at their home. They may then return home if their symptoms stabilised and continue to be supported by the hospice at home team until their death. This care approach is known as the 'care continuum' and you can learn more about how the care continuum applies to community-based specialist palliative care services in Appendix D.

9.6 The important role of community-based specialist palliative care in supporting system flow and improved outcomes for patients

For our emergency departments and wider parts of the acute hospitals (for example discharge hubs), the interface (a connection and interaction point) with both specialist and generalist community teams makes a difference to the patients involved and those important to them. Sectors and teams working together closely and effectively is key and this leads to better outcomes for patients, improved services, and better coordination of care.

We recognise that where people are in hospital who don't need or want to be there, this impacts on the acute hospitals' wider system capacity to support other people with acute medical needs. There is a need to improve the coordination and communication between emergency department teams, discharge hubs, and community teams, particularly when it comes to palliative and end-of-life care.

We described earlier the disparity between the numbers of people who say they want to die at home, versus those who actually do get to have their preference delivered on. Whilst this is not entirely down to specialist services, developing our model will clearly enable us to support more people in the community and thus this shift in terms of supporting more of people's preferences.

Through enhancing and strengthening our community-based specialist palliative care services, and improving our ways of working as part of the new model of care, we aim to:

- Prevent unnecessary admissions and reduce the burden on emergency departments and acute hospitals.
- Help our hospitals navigate what can be a complex number of community palliative care services.
- Make sure that the right care is provided when patients arrive at the hospital.

- Make sure there are smoother and faster patient discharges for patients who are ready to leave the hospital and can receive more appropriate care elsewhere.

The services within the new model of care that will support delivery of this are:

- **24/7 specialist palliative care telephone advice** - available for known and unknown patients, families and carers and clinicians via community-based specialist palliative care providers. This supports individuals to have access to expert guidance and signposting without needing to attend a hospital. It supports the reduction of unnecessary hospital admissions, and enhances patient care and family and carer experience particular out of hours.
- **More end-of-life care community specialist in-patient bed capacity**- through the introduction of enhanced end-of-life care beds available to all of NW London residents, more patients will be able to receive appropriate bed care to meet their needs outside of an acute hospital or hospice in-patient unit.
- **Extended operating hours for adult community specialist palliative care teams to provide care at home** - consistent adult community specialist palliative care teams, with longer working hours (7-days, 8am to 8pm) will enable more patients to receive this expert care in the community, particularly out of hours (after 5pm) when we know the access to other community support services and primary care is often challenging.
- **Enhanced and expanded hospice at home care service** – a consistent hospice at home care service, that can provide up to 24-hours of support working closely with other community care teams. The service is available to all boroughs in NW London and is beneficial in further reducing hospital admissions and speeding up discharge for patients who prefer to receive care in the comfort of their own home.

However, more needs to be done to streamline the link from emergency department teams and discharge hubs into our community palliative care teams and services, which goes beyond just community-based specialist palliative care services. This could best be described as setting an objective to make it simpler for hospital staff to communicate with services beyond the hospital and for patients to easily reach these services once they have left the hospital.

Whilst this document and the new care approach do not define the details of what this might look like, we are dedicated to collaborating with our acute palliative care consultants, emergency consultants, discharge hubs, generalist and specialist palliative care community-based services and primary care teams to develop these ways of working and improve the ease of access to generalist and specialist community palliative care services .This way we aim to reduce the burden on busy emergency department teams when it comes to coordinating and guiding patients to community-based care that is available.

In addition to making acute and community sectors work together better, our goal through this model and ongoing work to foster more collaboration, is to build strong partnerships among our different community services, as well as within community-based specialist palliative care services themselves. By improving how we communicate, and coordinate care, we can offer more seamless care across community services, primary care, social care, and our specialised community palliative care. This is aimed at reducing avoidable hospital admissions and enhancing the overall healthcare journey and experience for patients with serious illnesses and their families.

The overall aim is to create a more streamlined process for accessing and delivering community-based palliative care services. This collaboration is crucial in developing effective ways of working and robust processes to access the right care at the right time.

10. The three care service areas and their core service offers explained

There are three service areas included in the model of care that will support the patient and their family and those important to them at different stages of their illness depending on their preferences and clinical needs.

Wrapped around the community-based specialist palliative care services is the less clear role of 'care coordination'. Coordinating care is crucial across all palliative care, not just the specialist services, especially for patients residing at home. To support better coordination:

- Information should be shared through shared care records.
- Multidisciplinary team working - different specialists working together as a team across services and sectors.
- Service providers need to have simple access points for coordinating services within their organizations.
- Supporting roles that work behind the scenes to follow up actions and administrative tasks, thereby freeing up clinicians to focus their time on clinical care delivery.

10.1 Service area 1: Care at home

The model of care describes three different services which support people in their home and usual place of residence in the community. These are:

- Adult community specialist palliative care team
- Hospice at home
- 24/7 specialist palliative care telephone advice

These three services work together and link to generalist palliative care services like district nursing and general practice, and specialist palliative care in hospital. There are a number of ways that these services join up, for example via multidisciplinary teams (MDTs) and shared care records such as the London-wide Universal Care Plan (UCP) which is a digitally shared personalised care plan for people at end-of-life The UCP is key to supporting patients’ wishes and preferences being communicated and facilitated across the health and care system.

10.1a: Adult community specialist palliative care team

What we mean by the adult community specialist palliative care team?

The adult community specialist palliative care team consists of consultants, doctors, and clinical nurse specialists who provide essential support to patients with advanced and life-limiting illnesses in their home or usual place of residence.

They prioritise aligning care with patients' preferences, offering symptom management, emotional support, and assistance with advance care planning. The aim is to make sure the patient has comfort, dignity, and overall well-being during the palliative and end-of-life journey.

The adult community specialist palliative care team facilitate referrals to other community services, as well as other services within community-based specialist palliative care. They collaborate with other health care professionals such as GP, district nurses, social workers, therapists, and hospice teams to reassess patient needs and tailor comprehensive assessments and support for patients, families, and those important to the patient.

The aim is to provide effective medical support, coordinated care, and access to the necessary resources they need to support patients at their home. They also provide training to enhance the understanding of palliative and end-of-life care among care home staff, informal caregivers, and community clinicians.

Current adult community specialist palliative care nursing team provision in NW London:

In 2021/22, more than 6,500 individuals were under the care and support of the adult community specialist palliative care teams in NW London. By 2033, we expect this to rise to 7,700 people each year, a growth of 17%.

Adult community specialist palliative care nursing team support is provided across NW London by a combination of four non-NHS hospices, an NHS hospital provider and community NHS trusts. Each of the eight boroughs has access to adult community specialist palliative care team provision as follows:

Area	Which provider offers adult community specialist palliative care team services in each borough, and what are the service names?
Brent	• St Luke's Hospice (North Brent Community Specialist Palliative Care Team) covering north of the borough • Central London Community Healthcare NHS Trust (Pembridge Palliative Care Services' – Adult Community specialist palliative care nursing team) covering south of the borough
Ealing	• London North West University Healthcare NHS Trust (Meadow House Hospice Community team)
Hammersmith & Fulham	• Royal Trinity Hospice (Community specialist palliative care team) covering south of the borough • Central London Community Healthcare NHS Trust (Pembridge Palliative Care Services' - Community specialist palliative care nursing team) covering north of the borough
Harrow	• Central London Community Healthcare NHS Trust (Harrow adult specialist palliative care nursing team)

Hillingdon	• Central and North West London NHS foundation trust (Hillingdon Adult Specialist Palliative care nursing team)
Hounslow	• London North West University Healthcare NHS Trust (Meadow House Hospice community team)
Kensington & Chelsea	• Central London Community Healthcare NHS Trust (Pembridge Palliative Care Services' - Community specialist palliative care team) covering north of the borough • Royal Trinity Hospice (Community specialist palliative care team) covering south of the borough
Westminster	• Central London Community Healthcare NHS Trust (Pembridge Palliative Care Services' - Community specialist palliative care team) covering north of the borough • Royal Trinity Hospice (Community specialist palliative care team) covering south of the borough • St John's Hospice (Community specialist palliative care team)

Why change is needed

Currently, the care available from our adult community specialist palliative care teams varies depending on where residents live. In Harrow this service does not operate seven days a week. It only operates five days a week, Monday to Friday from 9am to 5pm. In the others boroughs, support is offered seven days a week from 9am to 5pm.

The feedback from residents suggests the majority of people want to be supported at home, and spend their final days at home. However, this may not always be possible because they are not always able to secure face-to-face support from the adult community specialist palliative care team outside these hours during the week, and especially on weekends when there are fewer staff available.

Whilst each hospice has a telephone helpline available that offers specialist palliative care telephone advice 24/7, not having in-person care from the adult community specialist palliative care team after 5pm is still a problem. We want to provide our residents with the highest quality care and support, and this means having healthcare professionals with the right expertise available for longer periods in patients' homes.

The lack of a common minimum standard for the support provided by the current adult community specialist palliative care teams also presents a challenge for delivering the best care and outcomes for patients and those important to them. This is particularly evident when it comes to assisting patients in care homes and making sure the broader palliative care workforce receives consistent training and specialist support.

All adult community specialist palliative care teams currently provide some level of support to care homes (nursing and residential) but this is ad-hoc and varies across local boroughs and teams.

To address these issues, we need to extend the availability of our adult community specialist palliative care team working hours, establish consistent standards of care and expand training opportunities.

New model of care proposal for the adult community specialist palliative care team services

The recommended new model of care proposal will deliver for all NW London residents regardless of where they live:

- **Service admission criteria**: The service supports adults (18+) with advanced life-limiting illnesses (for example but not limited cancer, end-stage heart or lung disease, neurodegenerative disorders such as dementia and Parkinson's disease, or advanced organ failure) with complex symptoms requiring expert management and specialised palliative care input for these symptoms and support with advance care planning. Service admission decisions are based on comprehensive assessments of the patients' needs by the team, the patient and their family, and other services.
- **Service hours of operation:** Care will be provided seven days a week, from 8am to 8pm. A 24/7 specialist palliative care advice telephone line will be accessible outside these hours.
- **Referral route and how to access services:** To access the services provided by the adult community specialist palliative care team, individuals can be referred by healthcare professionals such as GPs, hospital teams, hospice teams, and community nursing teams. Residents also have the option to initiate a self-referral, but this will require additional clinical information to be provided from a healthcare professional involved in their care to support the referral process.
- **Where is care provided:** The adult community specialist palliative care team delivers care in residents' own homes or their usual place of residence in the community, which includes care homes (residential, nursing and learning disabilities homes), hostels, shelters, mental health facilities, supported living accommodations and prisons. They strive to create a comfortable and supportive environment wherever the resident prefers to receive their care.

Key care duties and essential elements of care:

- **Holistic assessment and personalised care**: The team conducts comprehensive patient-centred assessments and provides high-quality care that addresses complex medical, psychological, and social needs. They collaborate with other healthcare professionals and specialist teams to support personalised care in the patient's home or usual place of residence following assessment.
- **Symptom management**: The team works closely with patients' regular healthcare professionals and teams in the community to manage complex

physical symptoms, alleviate pain, and improve overall comfort at home or in their usual place of residence.

- **Personalised care planning**: The team involves the patient, their family, carers, those important to them and other health care professionals involved in their care to support personalised care planning, including advance care planning for patients. Clear information and instructions regarding the patient’s care needs and preferences are recorded on and shared via digital personalised care plans, for example the London Universal Care Plan (UCP) which is currently the recommended platform for urgent and end-of-life care plans in NW London and London. Regular reviews and updates of the UCP will supported alignment of care provided with the patients changing needs and preferences
- **Support for family, caregivers and those important to the patient**: The team provides practical advice and provides and arranges emotional support and assistance with identifying respite care options. This type of support is crucial in improving outcomes for these individuals and the patients they support.
- **Collaboration with other healthcare teams**: The team supports comprehensive and coordinated care by working closely with the patient’s GP and other community services, including social care, to support the setup of appropriate care in the home and respite care if needed. The team will refer and coordinate care arrangements for community specialist in-patient care bed admissions if required.
- **Emotional support**: The team offers or facilitates access to appropriate emotional and psychological support for patients, families, caregivers, and those important to them, based on identified needs through assessment.
- **Practical support**: Assistance is provided in arranging home adaptations, equipment, and technologies in collaboration with community services and social care to enhance residents' independence and quality of life.
- **Information and guidance**: The team provides information and directs individuals to available resources and support services, including home care options and financial assistance.
- **Use of technology**: The team uses digital technology when appropriate to support care for patients, including for example virtual consultations and appointments and meetings with other health care professionals involved in patients’ care, enabling patients to receive more personalised care in line with their wishes in their home or usual place of residence and more co-ordinated care.
- **Supporting patient preferences about care/ death**: The team respects and strives to facilitate the patient's preferred place of care and preferred place of death whenever possible, by creating a supportive environment regardless of this care setting and working closely with other community-based specialist palliative care and community services. This involves case management and liaison with other healthcare providers, and making sure necessary support is in place for the patient, family and carers.

Additional support for care homes (residential and nursing)

- **Consistent care home (residential and nursing home) in-reach support for patients in standard residential or nursing home beds:** If a patient with specialist palliative care needs resides in a residential or nursing home, the adult community specialist palliative care team offers in-reach support within that setting to these patients. They work closely with the care home staff and multidisciplinary teams (MDT) to provide expert consultations, assessments, guidance, personalised care planning (including advance care planning), education and training for staff, emotional support, communication and collaboration, and assistance in transitioning to other places of care if needed. They will support this case management for patients in standard nursing or residential care home beds as appropriate. Patients with complex specialist palliative care needs in care homes should be able to expect the same level of specialist palliative care expertise and support that a patient in their home would receive.

- **Training and education to the staff:** The adult community specialist palliative care team will provide training and education to the nursing and health care assistant staff who are providing care, equipping them with a better understanding of patient needs and the skills to provide appropriate care and support.

Additional support for the system

- **Supporting the delivery of new dedicated enhanced end-of-life care beds available to all boroughs in NW London**: The care received in these beds by specialist trained nurses is of a greater complexity and intensity for patients with palliative needs. In cases where patients require 24-hour nursing care and specialised palliative care input but do not meet the admission criteria for hospice in-patient beds and cannot or do not want to remain at home, admission to enhanced end-of-life care beds may be necessary. These beds offer trained nurses, supported by the adult community palliative care team, who can provide the required level of care while also respecting and supporting patients' wishes to remain out of the hospital setting. This approach aims to reduce inappropriate and avoidable hospital admissions.

What will be different

The new model of care will boost the quality and accessibility of the adult community specialist palliative care team services through:

- **Consistent seven-day service and equal care across all boroughs:** Services are available 7-days a week, offering needed support during evenings and weekends. All residents, regardless of location, will have access to high-quality care. This is a step up in care from the current situation where coverage varies across boroughs. This will include strengthened weekend workforce arrangements to ensure consistent, uninterrupted care for residents.
- **Extended hours 8am to 8pm:** Unlike the current 9am to 5pm services, the new model extends support hours, offering help in early mornings and evenings (note – this service does not include rapid response).
- **Increased in reach support to care homes and supervision of enhanced end-of-life care beds:** A higher level of standardised support to care homes, including specialist palliative care for patients and improved staff training, and

dedicated support for the delivery of the new enhanced end-of-life care beds that will be available to all boroughs.
- **Enhanced palliative care training for wider generalist palliative care workforce:** The wider community palliative care workforce, including care home staff, will benefit from improved education and training.

In summary, the new model of care promises more equitable, comprehensive, and responsive care from the adult community specialist palliative care team service. It addresses existing shortcomings and substantially improves the specialist palliative care landscape for all residents in the community with the increased enhanced end-of-life care nursing home beds.

10.1b. Hospice at home

What we mean by the hospice at home service

Hospice at home service provision and models vary greatly in the UK and there is no single national definition or common model. The services are typically provided by local hospice or community-based specialist palliative care providers.

Most commonly hospice at home services provide palliative and end-of-life care and support for individuals who wish to remain in their own homes during their final stages of life. The service consists of predominantly health care assistants who have had specialist training in palliative and end-of-life care and have access to registered nurses and palliative care consultants via the hospice MDT and 24/7 advice line, as well as the adult community specialist palliative care team, for medical advice as needed to support patient care. The services bring the expertise and compassionate care element of a hospice into the patient's home, focusing on comfort and quality of life for patients who are expected to die in less than six months.

The hospice at home services for NW London are typically provided for a period of 14 days (two weeks), though the duration can vary based on individual needs and case-by-case considerations.

Hospice at home care is an approach that recognises the importance of personal preference, comfort, dignity, and the desire to remain in familiar surroundings during the final stages of life. The goal of the service to enhance the quality of life for patients and their families during the final stages of a life-limiting illness, through close working with the adult community specialist palliative care team and the patient’s usual care team, including GP, district nursing, continuing health care and rapid response services, to support managing physical symptoms (for example relieve pain), and supporting physical, emotional and spiritual well-being for patients and those important to them.

The health care assistants from the hospice at home team visit the patient’s home to:

- Provide personal care assistance and help with daily activities such as bathing, dressing, grooming, and toileting, making sure the patient's personal care needs are met.
- Administer medication and support patient comfort.

- Support with providing respite breaks for family and carers as required including providing and arranging overnight sitting.
- Linking them with appropriate psychological and spiritual support to meet their needs.

Hospice at home nurses will support symptom management and other holistic needs and coordinate care with district nursing (which is an entirely separate service) and the hospice specialist multidisciplinary team (for example doctors, psychologist, spiritual advisors) as required. The hospice at home service complements and does not replaces existing care arrangements (such as social care and continuing health care). It aims to support patients to have comprehensive care at home, and often can also be put in place to bridge a gap in care and support to prevent a hospital admission or support a hospital discharge.

The hospice at home team can also facilitate access to other hospice services, such as complementary therapies, spiritual care and bereavement support, for a patient's family, carers or those important to them once the patient has died.

Current hospice at home service provision in NW London

In 2021/22, more than 1,000 individuals received care from hospice at home teams in NW London.

Area	Who provides hospice at home services in each borough
Brent	St Luke's Hospice (North Brent) St John's Hospice (South Brent)
Ealing	No service commissioned
Hammersmith & Fulham	No service commissioned
Harrow	St Luke's Hospice
Hillingdon	Harlington Hospice (and other partners) support a night service – day service not commissioned
Hounslow	No service commissioned
Kensington & Chelsea	St John's Hospice
Westminster	St John's Hospice

Why change is needed

The need for changes in hospice at home services in NW London arises due to patient preferences and the interlinked issues of service variation and inadequate coverage for all boroughs

There is increasing patient preference for receiving end-of-life care at home with research showing that most patients have a desire to spend their final days in the comfort and familiarity of their own homes[5].

Current hospice at home services differ across the boroughs of NW London, resulting in inconsistent levels of patient care based on geographical location.

Some boroughs, such as Hammersmith & Fulham, Ealing, and Hounslow, lack dedicated hospice at home services. Hammersmith & Fulham, in particular, lacks any hospice at home care during both day and night. Although Ealing and Hounslow have overnight nursing and healthcare assistant care support provided by Marie Curie Nursing London, there is still a need for more comprehensive hospice at home services in these boroughs, particularly during the day.

To address these issues and provide this patient-centred care service consistently for all residents of NW London that require it, changes must be made to NW London hospice at home services.

New model of care proposal for the hospice at home service

The recommended new model of care proposal for the hospice at home service will deliver for all NW London adults nearing end-of-life, regardless of where they live in NW London, personalised, culturally sensitive, expert, and compassionate care in their homes. This care can be available around the clock, for up to 24-hours a day if need. The core service offer includes:

- **Admission criteria and service location**: The service will support adults (18+) with advanced life-limiting illnesses with a terminal prognosis (less than six months to live). This will include those with specialist palliative needs and those with non-specialist palliative and end-of-life care needs. They will uphold the patients comfort, dignity, and preference to stay in their familiar surroundings at home during their final stages of life. Hospice at home is available to patients at their home and usual place of residence including residential care homes, sheltered housing and homeless shelters.
- **Service duration**: The service will typically be offered for a standard duration of 14 days (two weeks), although there will be flexibility to adjust this on a case-by-case basis dependent on individual needs and circumstances.
- **Service support hours:** Hospice at home services will deliver round-the-clock care (up to 24-hours of care) for patients requiring single handed care. If double handed care is required the services will work in close collaboration with other community health services providing support in the home, including continuing health care teams, care home staff and domiciliary care provided through the council, to support 24-hour care.
- **Workforce:** The service will be delivered by a team of healthcare professionals, nurses and health care assistance who possess specialist training in palliative and end-of-life care**.**

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[5] National Survey of Bereaved People (VOICES - Views of Informal Carers - Evaluation of Services), England, 2015

The hospice at home service provides comprehensive care and support to patients and their families during the end-of-life journey. The key elements of the service are:

- **Collaborative and integrated care**: The service works closely and in partnership with other community health services (this includes CHC and social care input) to deliver round-the-clock (24-hour care) if required that complements rather than replaces existing arrangements. The goal is to support patients to stay in their preferred home environment during their final weeks of life, providing additional personal and respite care beyond social care and community services.
- **Workforce with enhanced palliative and end-of-life care knowledge and skills**: The service is primarily provided by health care assistants and registered hospice nurses who have enhanced training in palliative and end-of-life care through the support of the hospice specialist MDT. They work in collaboration with the patient's primary care team, community-based specialist palliative care teams, and hospice multidisciplinary teams to deliver expert and compassionate care.
- **Additional care support:** This includes escorting patients to out-patient appointments.
- **Crisis management and hospital discharge support**: Provides rapid care provision in to the home to support hospital discharges and prevent hospital admission (for example with informal carer stress).
- **Carer support:** Recognising the vital role of the patient’s informal carers, the service provides additional support for those looking after patients. This includes respite care (including overnight sitting and nursing support), providing temporary relief and allowing carers to rest and take care of their own well-being. Also includes emotional support, and referrals to other community and hospice wellbeing services (for example complementary therapies, spiritual care) as needed.
- **Pain and symptom management:** The team collaborates with other appropriate healthcare professionals to effectively manage pain and alleviate distressing symptoms, improving the patient's quality of life while receiving end-of-life care at home.
- **Emotional and psychosocial support**: The team provide and facilitate access to appropriate emotional support for both the patient and their loved ones according to their needs.
- **Personal care and assistance**: Assistance is provided with daily activities such as bathing, dressing, grooming, and toileting, ensuring the patient's personal care needs are met. This can be in addition to the social care and continuing health care arrangements already in place. The team will work closely with the social care and continuing health care team to co-ordinate level of care required.
- **Spiritual support and culturally sensitive care**: The teams respect and honour the individual beliefs, preferences, and practices of patients and their families, providing spiritually and culturally sensitive care and facilitating access to appropriate specialist care as required.
- **Bereavement support**: Following the patient's death, the hospice at home team continue to provide support to family members and loved ones, helping

them navigate the grieving process and offering ongoing assistance via onward referral to hospice bereavement support services.
- **Fast track care collaboration**: The hospice at home service closely collaborates with the NHS continuing healthcare team and fast track care providers to make sure there is swift and efficient care for patients with rapidly deteriorating conditions. This cooperation allows patients urgent access to necessary healthcare resources.

What will be different

The new model of care will boost the quality and accessibility of the hospice at home team services support through:

- **Consistent service and equal care across all boroughs:** Dedicated hospice at home services will be available seven days a week for up to 24-hours of care if assessed as needed.
- **Better integration and collaboration with other community teams involved in patient's care:** To support a more seamless care experience for patient and their families, carers and those important to them.

The new model of care for hospice at home services will be expanded to make sure all NW London boroughs have dedicated hospice at home services available and the variation in these services will be reduced by the implementation of care support up to 24-hours. This will include overnight sitting which will be based on patient, family and carer needs.

The hospice at home services will work more in tandem with other community services (for example adult community specialist palliative care team, community nursing, continuing health care, primary care and rapid response services) to achieve continuous care if required. They will support meeting the medical, psychological and spiritual needs of patients in the home who are nearing their end-of-life The hospice at home services will complement other care services already supporting the patient at home and not replace them.

To support hospital discharge and prevent hospital admission the hospice at home services will also provide 'bridging' care for up to two weeks whilst waiting for other more appropriate care arrangements to be set up for the patient for the longer term.

10.1c. 24/7 specialist palliative care telephone advice

What we mean by 24/7 specialist palliative care telephone advice

24/7 specialist palliative care telephone advice services provide round-the-clock expert palliative and end-of-life care guidance for patients, families, caregivers, and health and social care professionals including:

- **Immediate support and expert medical advice:** The primary focus is on offering immediate telephone expert medical advice and signposting for adults with life-limiting illnesses, their family, carers, those important to them and clinicians supporting their care.

- **Symptom management (for example, for pain):** Providing practical advice, help with navigation of other local services and addressing any other concerns, which is particularly important outside of the usual hours of operation of other palliative services (whether specialist or generalist).

The 24/7 specialist palliative care telephone service doesn't coordinate or arrange ongoing care or provide 24/7 hour visiting itself nor does it replace emergency services or provide long-term mental health support, financial aid, or legal advice.

Current 24/7 specialist palliative care telephone advice provision in NW London

In 2021/22, more than 1,500 people accessed the 24/7 advice lines available in NW London.

There is no single centralised NW London 24/7 specialist palliative care advice line service. Instead each of the hospices providing services in the eight boroughs offer individual 24/7 specialist telephone advice services. In addition, these services are also provided by community NHS trust specialist palliative care services in some boroughs (see table).

Borough	Current providers of 24/7 specialist palliative care telephone advice line services by borough
Brent	• St Luke's Hospice (Pall 24 service) - North Brent only • Central London Community Healthcare NHS Trust's Pembridge Palliative Care Services - all of Brent • St John's Hospice • Marie Curie Hampstead Hospice
Ealing	• London North West University Healthcare NHS Trust's Meadow House Hospice services
Hammersmith & Fulham	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care Services • St John's Hospice
Harrow	• St Luke's Hospice (Pall 24 service)
Hillingdon	• Harlington Hospice and Michael Sobell House in-patient unit • Central North West London NHS Foundation Trust's Hillingdon Your Life line 24 service
Hounslow	• London North West University Healthcare NHS Trust's Meadow House Hospice services

Kensington & Chelsea	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care Services • St John's Hospice
Westminster	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care Services • St John's Hospice

Why change is needed

The key challenge relates to the variability of 24/7 specialist palliative care telephone advice across NW London. Whilst all boroughs have 24/7 advice lines in place, some services do not consistently support unknown patients, i.e. patients who have not previously received care from community specialist palliative care services.

Some services also have differing levels of appropriately trained staff triaging calls and providing nursing and medical advice. This leads to inequities in the support and guidance patients can receive, depending on where they live.

New model of care proposal for 24/7 specialist palliative care telephone advice services

The recommended new model of care proposal for 24/7 specialist palliative care telephone advice services will deliver for all NW London residents irrespective of which borough they live in:

- A common core service that will bring personalised and culturally sensitive care, expertise, compassion, and comfort into the homes of adults in NW London with a palliative and end-of-life care need.
- The service will be delivered by a team of healthcare professionals including clinical nurse specialists and other palliative care nurses who possess appropriate specialist training and skills in palliative and end-of-life care.
- The service will support adults (18+) with advanced life-limiting illnesses, both those with specialist palliative needs and those with generalist palliative and end-of-life care needs.

The key elements of the service will include:

- **24/7 specialist palliative care telephone advice:** Offering NW London residents the expert guidance and support they need in relation to their palliative and end-of-life care related queries and needs. The advice line service will also extend beyond mere advice and information sharing. The teams will triage the needs of the callers and provide practical advice on symptom management as well as directing individuals to the most appropriate resources or services, whether that's suggesting other helplines (for example NHS111), local care provider websites, local support groups and other helpful organisations, or assisting with referrals to other more appropriate services when necessary.

- **Support for known and unknown patients:** For the first time all NW London residents whether known or unknown to community-based specialist palliative care services will be able to contact the 24/7 telephone advice line provided by individual borough providers (both local hospice and other community specialist palliative care providers). Known callers are individuals who have previously received care or are currently receiving care from community-based specialist palliative care services. Unknown callers are individuals who have not used the service before. Callers will be able to obtain expert advice and support with navigating care services, providing more equitable access for all. The 24/7 specialist palliative care advice lines will also be available to family members, caregivers, and clinicians in the local boroughs.
- **Specialised workforce:** The advice lines will be staffed by professional teams comprising palliative care nurses and clinical nurse specialists overseen by and with access to palliative care consultants who can provide direct advice when required. All teams will be trained to conduct comprehensive telephone assessments and triage, offering precise information and advice that addresses the specific challenges faced by patients.
- **Known patients and improved co-ordination of care:** For calls from known patients (and with the appropriate consent), advice line teams can use existing health care records and care plans to tailor their advice They can assist with complex medical situations, provide symptom management advice in line with patient's care plans, and help coordinate care with other healthcare providers as required.
- **Unknown patients and risk assessment, advice and support:** For calls from patients who are not known to the service currently, the teams may not be able to access complete clinical information for the patient, which may prevent them from providing comprehensive medical advice. They will still be able to provide some medical advice that aligns with safety guidelines, alongside a risk assessment. They will also offer general symptom management guidance, provide information about local resources, and help with navigation of and onward referrals for other community services.
- **Retaining local knowledge and expertise:** We are not recommending the development of a single centralised specialist palliative care telephone advice service or a single point of access for these services in NW London. We have carefully considered the challenges faced in coordinating and navigating palliative and end-of-life care, including generalist and specialist services. The complex infrastructure of our community services providing palliative and end-of-life care, and community-based specialist palliative care services, along with the potential risk of disrupting existing access points, prevent us from implementing this approach at a NW London level.

Implementing the new model of care for community-based specialist palliative care within this local delivery approach will help address some of the challenges faced in coordinating care and navigating the healthcare system for patients and their families.

We are aware that some community-based specialist palliative care providers (for example Royal Trinity Hospice) are currently developing their palliative and end-of-life care coordination services and some borough based partnerships (for example Hillingdon Health and Care Partners) are implementing local single points of contact and access for generalist and specialist palliative and end-of-life care.

We hope to evaluate and learn from these initiatives to support future iterations of the community-based specialist palliative care model of care and local delivery approaches going forward. Our aim is to ensure that individuals receive improved coordination, smoother transitions, and a more comprehensive approach to their palliative and end-of-life care. By working together with local stakeholders, we can continually improve the delivery of care and support for patients, their families, and caregivers.

What will be different

The key changes that the new model of care will bring are around equitable support and consistent expertise:

- Previously, services have not been consistently available to patient’s unknown to community-based specialist palliative care services, and the level of expertise of the staff supporting the advice line varied.
- In future, the service will be extended to all who need it, including known patients and those not already known to community-based specialist palliative care services, along with their carers, family and those important to them.

The teams will be led and supervised by a consultant in palliative care and staff who have been trained in palliative care including clinical nurse specialists and palliative care nurses. They will have appropriate training to support consistent, high-quality triage and provide expert palliative care nursing advice and support. 24/7 access to expert medical advice will be available via the consultant in palliative care.

10.1d. Continuing service developments alongside implementation of the proposed new model of care to best support people at home

During the development of the proposed new model of care, and following our recent engagement period on the model with a variety of stakeholders, we have heard many ideas for further improvements. Some of these suggestions are pilots already underway in NW London, regionally and nationally.

As we move forward, it is imperative that we maintain the flexibility to learn from these pilot initiatives and incorporate them into our model's future iterations as their impact becomes more evident. This adaptive approach is crucial not only for the ongoing improvement of our services but also to ensure that we can meet evolving requirements, including those introduced by the National Health Service England (NHSE).

However, while we acknowledge the potential value of these ideas and that we may need to incorporate them into service improvements, it's important to highlight that, at this stage, we do not possess the same level of observed evidence regarding their impact and value as we do for the core components outlined in the proposed model of care. These foundational elements are in alignment with the national specification and represent a well-documented evidence basis and approach. It will be important that for all of the following areas – and more as innovation emerges – we have flexibility to learn and roll out further changes. This includes responding to future requirements from NHSE such as on virtual wards.

Future developments for consideration as part of the model

Rapid response for palliative and end-of-life care needs
We have heard from our engagement and seen in the evidence that effective, responsive, and timely out-of-hours care improves the well-being of patients and families, and helps prevent unnecessary emergency hospital admission at end of life. This is essential as individuals living with advanced illness may experience health deterioration at any time, day or night.

The model of care working group fully recognised the importance of patients and their families and carers having rapid access to care and support and discussed inclusion of this as part of the new model of care.

Following scoping work, the group identified and discussed the various 24/7 rapid response services that are currently commissioned and delivered differently within each of the NW London boroughs. These are provided either by universal rapid response community services or specialist rapid response services and typically include:

- Dedicated rapid response services working 8am to 8pm for all boroughs
- Community district nursing services providing support during the day and some overnight with a two-to-four-hour response time.
- NHS 111 and out-of-hours general practice (GP) support services.
- Some NHS community-based specialist palliative care services and charitable hospice services provide dedicated rapid response services including the

Marie Curie end-of-life rapid response services in Ealing and Hounslow and St Luke's Harrow Pall 24 service and CNWL's your life line service. St Luke's Harrow Pall 24 services offers rapid home visits out of hours between 6 and 10pm, and CNWL your life line services offer rapid visiting in and out of hours.

The model of care working group discussed whether a common 24/7 specialist palliative care rapid response service should be included within the model of care but determined that rapid response services are currently being provided in each borough of NW London via universal community services, it should continue via this route to reduce duplication. From discussions within the model of care group amongst providers we heard that although there are occasions when rapid intervention from community specialist palliative care is required, from their experience the majority of the needs arising for patients with palliative and end of life care needs can be addressed by universal rapid response services (ie. district nursing, rapid response teams) and that the data to support intervention from community-specialist palliative care was limited at this time. As such specialist palliative care rapid response is not included in the recommended new model of care.

Royal Trinity Hospice is developing a new rapid response service for community-based specialist palliative care, based on their individual services data and scoping, which will start in the next few months. We will continue to engage with them about the service and its outcomes. Following robust evaluation, there may be scope to revisit including rapid response for community-based specialist palliative care services within NW London's new model of care in the future.

Hospital emergency department and rapid discharge support
This area is focused on enhancing integration and access to community-based specialist palliative care support for clinicians and patients in emergency departments. It entails creating improved referral pathways, ensuring a seamless transition between emergency departments and community-based palliative care services. For example, this support might include the establishment of a community-based specialist palliative care team that can swiftly respond to the needs of patients in the emergency department. Furthermore, it could involve the implementation of palliative care rapid response in-reach teams that work within the hospital to support admission avoidance for palliative and end of life care patients, thus reducing unnecessary hospital admissions and providing timely and appropriate care.

Care co-ordination service
A care coordination service could be developed, focused on streamlining and improving the coordination of care for palliative patients. In addition to facilitating better communication between various care providers, this service could potentially assist in ordering necessary equipment and connecting patients with the right services as needed. It could act as a critical link in the palliative care network, ensuring that patients receive the full spectrum of care they require. Royal Trinity Hospice currently provide such a service in the borough of Wandsworth. The charitable hospice sector alliance in development for NW London have expressed intentions to develop a care co-ordination service for NW London akin to the Wandsworth model that can could be piloted in future.

Hospice virtual ward support:
Currently national virtual wards allow patients to receive care in the comfort of their home through the support of remote monitoring equipment and a team of community staff. For specialist palliative care, having virtual ward care is a forward looking innovative approach that could support making specialist palliative care more accessible and flexible, meeting patients where they are and providing comprehensive care outside of traditional in-patient settings. In NW London, this could involve developing hospice or specialist palliative care virtual wards with the support of specialist palliative care multi-disciplinary teams (MDT). These teams consist of professionals with diverse skills and expertise, that enable them to address the various and often complex needs of palliative care patients. The potential development and expansion of virtual wards reflect our commitment to supporting more patients in their preferred place of care.

A single point of access for palliative and end of life care
Simplifying access to community-based specialist palliative care services is a priority for the new model of care. Work has already been undertaken as part of this new model with the development of a new service directory resource at NW London and local borough level (see: https://hpal.medindex.co.uk/p/t/palliative-care/services).

Through our engagement with stakeholders, we've identified a strong desire for a single point of access, either at the NW London or local borough level. We recognise the importance of creating an efficient and centralised system that benefits patients, caregivers, and clinicians and provides a straightforward and user-friendly way to access palliative care services and improve patient outcomes. A single point of access for palliative care is currently being developed and trialled in Hillingdon borough and we hope to learn from this initiative. We would not only be supporting the local implementation of the proposed new model of care in terms of partnership working but also inform future iterations of the model that may involve the recommendation of a local single point of access at borough level.

Each of these areas of development represents a critical aspect of our commitment to innovation and adaptability. We remain open to integrating new ideas and addressing emerging challenges in the field of palliative care as more evidence of their benefit becomes available. We aspire to build and maintain a model that not only reflects the core principles of our initial design but is also agile enough to accommodate new and innovative approaches to care, meeting the changing needs of our patients and any mandates introduced by NHSE.

10.2. Service area 2: Community specialist in-patient bed care

We received extensive feedback during our engagement indicating that our current hospice in-patient bed care services offer excellent support for patients and those important to them. However, we were also advised that this provision does not always meet the needs of our patients that require extra support but not the intensive level of specialist palliative bed care that a hospice offers.

This gap in the type of specialist in-patient bed care has been identified as particularly affecting individuals whose needs exceed them being supported at home or in a care home without any enhanced palliative care support but are not appropriate for a short term, intensive inpatient hospice admission. This is especially true for those with palliative and end of life care needs who are living alone without a local support system.

NHS NW London and the model of care working group is recommending the introduction of a new type of community specialist in-patient bed, the enhanced end of life care beds, in addition to keeping the existing specialist hospice inpatient beds.

The enhanced end-of-life care bed service aims to provide comprehensive and compassionate in-patient bed care for individuals with advanced illness and terminal conditions who are nearing the end of their lives. This service is supported by the adult community specialist palliative care team providing weekly visits from a clinical nurse specialist and a palliative care consultant, in addition to the registered nurses and healthcare assistants already working within the care home 24/7 who will have enhanced end-of-life care skills. The goal is to improve the quality of life for these patients towards and at end of their lives when their current care arrangements are no longer suitable for their needs, offering both patients and their families/carers increased support during this challenging and sensitive time.

These beds aim to create a therapeutic, calming, home-like environment, with the added benefit of access to hospice well-being services such as complimentary therapies and bereavement and psychological support if needed. We recognise that this type of enhanced bed care is best provided in a community setting, such as a nursing care home or community bedded unit with separate bedrooms, rather than a NHS hospital ward environment.

This type of in-patient bed care provision is currently available in the borough of Hillingdon only, where it has shown positive outcomes for patients to date.

Why change is needed regarding current specialist palliative care bedded care:

Public attitude and patient preference on place of death
There is data showing a fall in the use of in-patient hospice specialist palliative care beds as people choose to be cared for, and die at home[6]. Research and patient feedback shows that more patients have a preference to die at home rather than in

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[6] Support at the end-of-life (nuffieldtrust.org.uk)

hospital, however we do also recognise that in some cases it is appropriate for patients to be admitted to hospital at end of life and that hospital care is a preference for some patients

Increase in technology use to augment care

With increasing use of technology and enhanced community-based specialist palliative care support, we aim to provide more care for people in their own home through augmenting care with use of virtual consultations where appropriate. This will support hospice in-patient unit beds being used for the most appropriate patients with the most complex needs, and help to reduce the number of people being admitted inappropriately to hospital, thus reducing the burden on the hospital care system.

Staffing and recruitment challenges of key palliative care staff

There is an ongoing shortage of specialist palliative care consultants and specialist palliative care clinical nurse specialists. In NW London we are currently struggling to recruit to one of our in-patient bed units, resulting in suspension of the unit. This puts a strain on an already limited number of beds so we need to make sure the beds in in-patient units are available to those who really need them, and make best possible use of alternatives where this is appropriate.

Inequity in access and gaps in in-patient bedded care provision

Our travel mapping analysis (analysis of travel patterns) has shown that certain parts of NW London do not have a hospice in-patient unit within a reasonable distance of travel, whilst some other areas have multiple options for in-patient units available to them. This had led to an inequity of access based on where a patient lives and means patients, families and carers having to travel further to get the support they need. Increasing care provision to help people stay in their own home and the introduction of enhanced end-of-life care beds offer the prospect of improving access to quality specialist and enhanced palliative care. Thereby better supporting those residents who currently have a poorer service based on where they live in NW London.

Variation in existing service provision

At present, some of our hospices do not routinely admit patients seven days a week for planned and unplanned care, leading to an inequity of access. They also have differing admission criteria, which can be difficult for public and clinicians to understand.

Variation in patient needs resulting in a continuum of specialist palliative care needs

Often a patient with palliative and end-of-life care needs reaches a point where they are no longer able to stay in their own home or usual place of residence due to challenging physical and/or social circumstances and therefore their health and/or social care needs cannot continue to be managed by their usual care teams at home (for example, hospice at home service, adult community specialist palliative care team, continuing health care or district nursing team support).

For some of these patients their needs may be extremely complex and they will require a short term admission to a hospice in-patient bed for intensive daily support from a hospice inpatient multi-disciplinary team.

However, some of these patients may have more less complex palliative care and end of life care needs or slightly less complex needs but still need 24-hour nursing, or the patient does not want to die at home or in hospital. This is especially true for those living alone without a local support system. However, their specialist palliative care needs may not need to be managed in a hospice in-patient bed unit and can often be better supported in an alternate bedded care setting such as a nursing home bed or enhanced end of life care bed.

We received extensive feedback during our engagement indicating current hospice in-patient beds were not required for some patients and the patient could receive more appropriate care in a different setting. Or that these types of bed and environment did not always meet the diverse needs of our patients requiring this type of specialist support.

Results of a collaborative hospice inpatient bed audit

- We received feedback from our specialist clinical teams during our engagement indicating current hospice in-patient beds where not required for some patients with specialist palliative care needs and that some patients currently admitted could receive more appropriate care in a different bedded care setting (for example a nursing home bed or enhanced end of life care bed if these were available across NW London). We were also told that hospice in-patient beds and the hospice environment did not always meet the diverse needs of our patients requiring specialist support.
- In response to this feedback, ongoing engagement and as part of our continuous efforts to improve our hospice in-patient services bed capacity usage, a joint clinical audit of hospice in-patient admissions was conducted across all five hospices (charitable and NHS Trust) currently providing in-patient bed services to NW London.
- The audit objective was to better understand the utilisation of our specialist hospice in-patient beds and to explore our hypotheses that some patients being admitted to these beds would have their palliative care needs better met within alternate care settings such as nursing homes or enhanced end-of-life beds. Understanding this information would also help us in determining current unmet demand for these enhanced end-of-life care beds.
- The audit involved a review of 100 consecutive hospice admissions across five in-patient units in mid-January 2023. Of those 100 admissions, 24 cases had insufficient information to be included in this analysis, leaving a relevant sample population of 76 admissions.
- Of the 76 sampled admissions, 20 cases (26%) were determined to have been more appropriate to have their needs met with alternative care such as nursing home care (14 cases) or enhanced end-of-life care beds (6 cases), if this second type of provision was available in the community.

Audited hospice in-patient admissions population information:	**Cases**	**%**
Cases with sufficient feedback for alternate care setting analysis (out of 100 in-patient bed admissions audited)	**76**	**--**
Cases deemed more suitable for nursing home care than in-patient hospice care	14	18
Cases deemed more suitable for enhanced end-of-life care beds	6	8
Total cases where alternate care settings were identified as more appropriate	**20**	**26**

- NW London has a total hospice in-patient bed capacity of 57 beds. To put the above audit findings into perspective, if we relate these figures back to these 57 beds it shows that if those 14 patients (10.26 of 57 beds) deemed more suitable for nursing home, and the 6 patients (4.56 beds of 57 beds) deemed more suitable for enhanced end-of-life care beds had been supported in these alternate care settings, 14.82 hospice in-patient beds could/should have been made available (see table below).

Most appropriate bed care setting	**Cases**	**Percentage**	**Equivalent NW London hospice in-patient beds (57 in-patient hospice bed capacity)**
Hospice In-patient beds	56	74%	42.18
Nursing home bed	14	18%	10.26
Enhanced end-of-life care bed	6	8%	4.56
Total	**76 cases**	**100%**	**57 beds**

These findings validate the need to introduce enhanced end-of-life care beds as part of our new model of care. This will not only optimise hospice in-patient bed capacity and usage to support those who need it most, but, more importantly, it will offer a wider and more appropriate range of specialist palliative care bed options in the community, ensuring appropriate care at every stage of our patients' palliative journey. It may also help avoid unnecessary or inappropriate admissions into hospital.

Summary of the main changes for community-based specialist in-patient bed care as part of the new model of care:

- There will be an overall increase in the number of community-based specialist palliative care in-patient beds following the introduction of 54 dedicated enhanced end-of-life care beds across all of NW London. These new beds will cater for the needs of patients who do not require an intensive, short stay hospice bed but cannot stay at home due to their specialist needs, do not wish to stay at home, do not want to or do not need to be in a hospital and their needs exceed a usual care home.

- We will maintain the current number of hospice in-patient unit beds (57) to support our patients with the most complex specialist palliative care needs to receive bed care, but enhance this provision to support 7 days a week admissions for residents regardless of the borough they live in.

10.2a. Introducing enhanced end-of-life care beds across NW London

What do we mean by enhanced end-of-life care beds?

The NW London model of care working group has recommended an increase in the number of dedicated specialist palliative care in-patient beds available in the community to NW London residents, through the introduction of enhanced end-of-life care beds across all boroughs in NW London.

Aim of these beds
These beds aim to provide compassionate dignified care in a dedicated appropriate space for individuals at the end of their (approximately 3 months' life expectancy) and where their palliative and end of life care needs exceed what their usual care teams can provide in their usual place of residence including a care home, or where they do not want to die at home and do not need or want to go to hospital. They are intended to support these individuals in living their final days with as much comfort, support, and quality of life as possible.

Difference between enhanced end of life care beds and care home beds
Care homes (residential and nursing) provide long-term care bed facilities that cater to individuals who may have chronic illnesses, disabilities, or age-related health issues that require 24-hour assistance with daily activities. These individuals may go on to require end of life care support at a point in time while being in a care home bed. If nursing input is required for the patient due to change in needs they move to a nursing home where they received nursing care, but nursing homes are not exclusively for end-of-life care patients and not everyone in a nursing home bed is receiving end of life care. Currently in NW London the adult community-based specialist palliative care team do support patients who reside in a care home beds and have specialist palliative care needs. This support is usually through training for the care home staff in how best to manage the patients' symptoms.

The key difference is that the enhanced end of life care beds will have staff with enhanced training on specialist palliative care, alongside planned weekly support from the community specialist palliative care team including a consultant and community nurse specialist whereas community specialist palliative care nursing team support for residential and nursing homes is more adhoc and case by case based rather than dedicated ward rounds by the specialist being carried out regularly and in-house staff with increased palliative care nursing skills

Location of these beds

These 54 dedicated beds will be located either in existing community in-patient bed services units or other care settings (for example in nursing care homes or other community bedded units).
The number per borough will vary depending on:

- Local borough population needs.
- Local borough in-patient unit bed infrastructure availability and nursing care home provider market.

Details on the exact location of these beds will be worked through as part of the implementation phase of this work which will be led at borough / “place” level.

Staffing model
The care in the enhanced end of life care beds will predominantly be delivered by nurses and health care assistants, who will be upskilled in palliative and end-of-life care through the support of local hospice(s) and adult community specialist palliative care teams. If the beds are to be set up in nursing care homes, we would be looking to upskill existing staff, whereas if they are to be set up in other existing bedded units that may be unused, it is likely we may need to hire and upskill some new staff to support care delivery in these units.

The beds will also be supported by the adult community-based specialist palliative care team with a clinical nurse specialist and palliative care consultant who will conduct dedicated once weekly ward rounds.

In addition, the patient and their family/ carers will also receive support from local hospices well-being services and specialist palliative care multi-disciplinary team depending on their needs. For example, this could include visits from a hospice matron, psychological support services, complimentary therapy teams. Family/ carers will also have access to hospice bereavement support services.

The adult community specialist palliative care team will collaborate closely with the staff of the enhanced care beds, the patients GP and the multidisciplinary team supporting the patient’s care in community to make sure the patient receives the care they need. As outlined, they will provide weekly planned attendance at the enhanced care unit and additional training as needed for the staff to ensure the patient's comfort, dignity and overall well-being while receiving care in these beds.

Clinical governance and accountability
Although the specialist palliative care consultant will see each patient face to face for a weekly review, the medico-legal responsibility, which is the legal obligations and accountability for patient care, remains with the patient’s GP.

Key elements of the enhanced end of life care bed service

The enhanced end of life care bed service will offer:

- 24 hour care by nurses and health care assistants with enhanced end-of-life care skills (including communication, symptom control and identification and management of the end of life stage). With the training being

supported by the adult community specialist palliative care team and local hospice(s).
- Weekly face to face input from adult community specialist palliative care team and close collaboration with patient's registered GP.
- Access to hospice well-being services and other specialist professionals within the specialist palliative care team. This includes psychological and bereavement support for family/ carers.
- 7 day admissions for planned and unplanned admission.

The admission and discharge criteria for enhanced end of life care beds

- Patients should be registered with a North West London GP.
- All patients are to be considered based on individual needs, this includes for people experiencing homelessness.
- These beds are not disease specific and can be used for patients with cancer and non-malignant/ non-cancer palliative diagnoses.
- Patients should have a life-limiting illness with a prognosis of months and/ or nearing the end-of-life with a life expectancy of around 3 months. All patients will be considered based on individual needs
- The patient requires enhanced palliative and 24-hour end-of-life care that their regular care teams in the community i.e. district nurses, GPs, hospice at home, social care package, or continuing health care, cannot provide.
- Patients who cannot or do not want to receive care at home due to medical needs, social circumstances, or lack of necessary equipment but their needs do not meet the specific, short term support of a specialist palliative care hospice in-patient unit.
- The anticipated length of stay is up to three months, but this may be more or less depending on the patient's needs.
- Referrals for admission to these beds may come from the patient's GP, the adult community specialist palliative care team, hospice at home, care homes, community district nursing, hospice in-patient unit, or hospital team.
- Patients can be stepped up to these enhanced beds from a care home (residential or nursing) through referral by care home staff and the adult community specialist palliative care team.
- Patients can also be stepped up to a hospice in-patient unit bed from these enhanced end-of-life care beds through referral from the community specialist palliative care team, GP, and community nursing (including district nursing, rapid response nursing, specialist heart failure or respiratory nursing). The hospital or hospice in-patient unit can refer and discharge patients (step down) to these enhanced end-of-life care beds.

Referral route

- For admissions from hospitals, all patients should be medically assessed and referred by a specialist palliative care doctor prior to transfer.
- For admissions from the community, all patients should be medically assessed and referred by their GP and/or community specialist palliative care team prior to transfer.

Patient stories from Hillingdon's enhanced end of life care bed service:

Patient vignette 1: Mrs A

Mrs A was a 56-year-old lady with a brain tumour. She was referred to the community specialist palliative care team in Oct 2020. Initially Mrs A wanted low level support from the team and the main support was for her daughter who was her main carer. In December 2020 Mrs A became less well, drowsy and had reduced cognition and oral intake.

Mrs A's daughter was struggling to cope with caring for her mother and their preference was for care to be given in a local nursing care home, although the community specialist palliative care team thought an inpatient bed unit may be a better fit due to Covid-19 pandemic restrictions (care homes had limited visits to less than hospices). Mrs A's daughter was scared of the dramatic decline in her mother's health that she was observing and home care interventions were put in place, such as continuing health care (CHC), carers support and hospice at home respite day support. Steroids were also prescribed to help manage and stabilise her deterioration due to her raised intracranial pressure symptoms of speech and swallow problems and seizures.

In January 2021 Mrs A's daughter could no longer cope with caring for her mother at her home. She had reached a crisis point with her friends concerned she may self-harm if she remained responsible for her mother much longer. Mrs A agreed to change her care setting as she required 24-hour care support to manage her symptoms and to give her daughter a break The patient's daughter spoke with the community specialist palliative care team's palliative care consultant. Given her mother's need for 24-hour care, the need for more input for her symptom control (including seizures and pain management), her ow struggle to cope with caring for her mother at home despite the additional home care support and the likelihood her mother will need longer care than an in-patient hospice bed would offer, all agreed to a referral to an enhanced end of life care bed

Mrs A was admitted to an enhanced end of life care bed within a nursing home in January 2021 and died peacefully in June 2021. The community specialist palliative care team made the decision to extend Mrs A's stay beyond the usual three months' as Mrs A's needs were being well met, she was happy in the enhanced end of life care bed within the nursing home and transferring her back to being cared for at home was not an appropriate option for her.

In the final month of her life Mrs A needed a syringe driver to replace the anticonvulsants she could no longer take by mouth, and she needed to have her steroids carefully titrated against physical/cognitive symptoms.

Mrs A's daughter was very pleased to have her mother's needs met in the nursing home and she engaged well with the community specialist palliative care team's psychological support service to help her in her pre-bereavement phase leading up to her mother's death.

Patient vignette 2: Mr B

Mr B, a 54-year-old man with a grade 3 Glioma (brain tumour), was referred by the hospital team to the borough community specialist palliative care team in November 2019.

Mr B lived alone when the community-based specialist palliative care met him for the first time. He was divorced with adult children and local supportive sisters who visited and initially helped with domestic needs. Over time Mr B began to need increased support due to changes in his physical and cognitive health.

Mr B remained at home with support from November 2019 until April 2022, when it became evident that Mr B’s care needs were becoming too complex to be effectively supported by the community specialist palliative care team and other health and social care support in his home. At this time, he had unstable diabetes, increased cognitive changes and unstable symptoms of nausea and vomiting needing specialist steroid dosages to manage. It was not safe for him to be left alone at home during gaps in his care support and he had no family who could stay with him.

Given Mr B’s increasing complexity of needs and rapid decline in health at home, a multi-disciplinary team discussion in collaboration with Mr B and his family took place, and it was agreed that Mr B should be admitted to an enhanced end of life care bed within a local nursing home. Although his symptoms were more complex than could be managed at home, he did not require the full support of a hospice inpatient unit and the associated daily input from specialist palliative care staff. However, he did require 24 hour nursing care with weekly input from the community specialist palliative care team. He was subsequently referred, based on his needs and wishes, to an enhanced end of life care bed within a local nursing home. He remained there until the July 2022 when he passed away.

During his time in the unit his family were able to visit and spend time with him, including family from the USA. His family were very pleased with the care Mr B received in the enhanced care bed. His steroids were able to be adjusted by the community specialist palliative care team’s consultant and clinical nurse specialist (CNS) during his stay based on his physical needs and, in his last days of life when he was unable to swallow and needed his anticonvulsant medications to be given a syringe driver. The enhanced care home bedded staff had the necessary skills to support this.

Patient vignette 3: Mrs C

Mrs C was a 48-year-old lady with a terminal brain tumour with two teenage children. She was known to the community specialist palliative care team from Spring of 2020 until her death in an enhanced end of life care bed unit in November 2021.

Mrs C managed quite well at home with the support of the community specialist palliative care team, district nursing team, her GP and continuing health care (CHC) funded home care until she became bed bound, needing a greater level of nursing care and regular review and adjustment of her medications to treat her recurrent seizures.

The other complication for Mrs C was that she was having difficulty swallowing (secondary to her brain tumour). This was leading to aspiration and recurrent chest infections. Mrs C's symptoms had become too complex for her usual care teams to appropriately manage her care at home.

When Mrs C had been able to state what she had wanted from her end of life care, she had been clear that she did not want to die at home and wanted to be transferred to a hospice.

Mrs C lived in the south of her borough and the hospice she had access to was in the north of the borough, meaning her family faced an approximate 12 mile trip for visits,

An enhanced end of life care bed was available within a nursing care home. This could reduce the family's travel to approximately 3 miles. Also, the community specialist palliative care team were of the view that, although Mrs C's palliative care needs were not straightforward, she could be appropriately supported by their team and the nurses in the care home based unit, rather than needing hospice inpatient care. A decision was taken together with Mrs C and her family for her to go to the enhanced end of life care bed unit bed and she subsequently had a short but positive admission. Mrs C's one wish was that she and her family would be well supported at end of life and that she would not die at home. The enhanced end of life care bed unit was able to meet her and her family's needs. She had a peaceful death with good symptom control and timely access to a syringe driver when it was needed. Another benefit from the family's perspective was the continuity of care provided by the specialist palliative care team from the community to the enhanced end of life care bed unit, with regular visits from both the palliative care consultant and the clinical nurse specialist when Mrs C was at home and then these same staff visiting in the enhanced end of life bed care unit through the weekly ward round.

Current provision of enhanced end-of-life care beds in NW London

There are at present eight enhanced end-of-life beds in the borough of Hillingdon.

- The beds are located across two nursing homes, Hayes Cottage Nursing Home (HCNH), Grange Road, and Hayes and Parkfield House Nursing Home, Charville Lane West, Uxbridge.
- They are known in Hillingdon borough as the Primrose palliative care beds.
- A specialist palliative care consultant doctor and specialist palliative care nurse from the adult community specialist palliative care team visit the nursing homes once a week to support staff and patients in these beds.
- Patients and their family/ carers also receive support from local hospices (Michael Sobell and Harlington Hospice) well-being services and specialist palliative care multi-disciplinary team depending on their needs. For example, this could include visits from a hospice matron, psychological support services, complimentary therapist and therapy teams. Family/ carers also have access to the hospice bereavement support services.

The new model of care for enhanced end-of-life care beds will ensure all NWL London residents (irrespective of borough) have:

- An increased number of community specialist in-patient beds for patients who do need short, intensive hospice in-patient unit bed care but are unable to stay at home or their usual place of residence due to their needs and their preference is not to be treated in hospital. These dedicated beds will be in addition to, and not replacing, the current working hospice in-patient unit beds we already have in NW London.

- The new model of care will introduce 54 enhanced end of life care beds for NW London in totality. There is no benchmark for the number of beds required, as this is an innovative addition to provision in NW London and regionally. There is no national or international evidence base for the number of beds needed, however following discussion the model of care working group agreed that a reasonable planning assumption, based on examples from elsewhere in NW London, is 2.5 beds per 100,000 populations. This was further ratified by scaling up Hillingdon's provision of eight beds for the whole NW London population. If we were to allocate this across all boroughs according to their population this would result in the following bed number per borough

Borough	**2023 population**	**Proposed number of enhanced end-of-life care beds per borough**
Brent	353,690	9
Ealing	380,722	9
Hammersmith & Fulham	188,103	5
Harrow	270,741	7
Hillingdon	315,198	8
Hounslow	300,880	7
Kensington & Chelsea	145,328	4
Westminster	211,814	5
NW London total	**2,166,475**	54

Summary: what will be different?

The introduction of 54 enhanced end-of-life care beds across NW London will increase the quality, number and accessibility of community in-patient specialist beds currently available to patients who need more support than what can be delivered in their existing home.

Patients will also have far greater access to this largely new, enhanced bed option, meaning those already in care homes will have a smoother transition to an enhanced bed, where required. Those living in their own home will receive appropriate non-hospital based support at the end-of-life if they cannot be supported to die at home and they do not need the short term intensive hospice inpatient bed.

10.2b. Hospice in-patient unit bed care

NHS NW London and the model of care working group have recommended that we retain the current level of specialist hospice in-patient beds following an analysis of projected population growth and expected need, coupled with the introduction of enhanced end-of life care beds.

What we mean by hospice in-patient unit bed care

Hospice in-patient unit bed care provides short-term, intensive, specialised 24-hour care in NHS specialist palliative care bed units or hospice facilities for individuals with advanced or terminal illnesses. A hospice in-patient admission is based on a patients' needs being unmet by all other services available. It includes supporting complex medical concerns**,** specialist rehabilitation, specialist respite care and specialist end-of-life care.

The main goal of hospice in-patient bed care is to provide the best possible quality of life and support for patients, their families, carers and those important to them during their last phase of life and end-of-life journey.

A multidisciplinary team of healthcare professionals, which may include specialist palliative care doctors and nurses, social workers, physiotherapist, counsellors and chaplains, work together to provide comprehensive care. Together they address the physical, emotional, and social needs of the patient. The hospice environment is compassionate and supportive, creating a home-like atmosphere that promotes emotional well-being and ensures patients' comfort and dignity.

The length of stay in a hospice can vary depending on individual needs. It is typically short-term (two weeks) but caters to the individuals need and circumstances should a longer stay be required. Care is focused on stabilising symptoms, rehabilitation, providing respite for caregivers, or offering terminal care. While some patients may pass away in the hospice facility, others may improve or stabilise under this specialised care. They will then leave the hospice to continue their care in a different setting, such as at their own home with hospice at home support or in a nursing home depending on their needs.

Current hospice in-patient unit bed care provision in NW London

We have five charitable hospices and two NHS fully-funded specialist palliative care service providers who are paid to provide hospice in-patient bed care to our NW London residents.

Central London Healthcare NHS Trust's Pembridge Palliative Care Service ("Pembridge Hospice") in-patient unit, has been suspended since 2018 due to challenges with recruiting and retaining a palliative care consultant for the unit. Arrangements have been put in place currently to support residents who would usually have used these specialist in-patient hospice beds so they could use hospice inpatient beds at another of the hospices in NW London while the unit remains suspended.

In 2021 nearly 1,000 NW London residents received in-patient bed care in one of our available NHS specialist palliative care or charitable hospice in-patient units. Please note that not all the charitable hospices are located in NW London and they cater for populations beyond our own within their in-patient units.

Overall, in 2021 we had 56 hospice in-patient beds serving our communities while Pembridge Palliative Care Services' in-patient unit remained suspended. There is no national benchmark for what the right number of hospice in-patient unit beds is for a population.

The table below shows the number of hospice in-patient beds commissioned by NW London by provider.

Number of NW London's annually commissioned hospice in-patient beds by provider in 2022-2023:

St Luke's Hospice	12
St John's hospice	7
Royal Trinity Hospice	9
Harlington Hospice (Michael Sobell House inpatient unit)	10
Marie Curie Hampstead Hospice	1
London North West University Healthcare NHS Trust providing Meadow House Hospice	15
Central London Community Healthcare NHS Trust providing Pembridge palliative care in-patient service	3 beds spot purchased at other inpatient units in lieu of Pembridge IPU being suspended
	57

The table below shows which hospice's in-patient units serve which boroughs in NW London[7]:

Area	**Who currently provides hospice in-patient bed care services in each borough?**
Brent	• St Luke's Hospice • St John's Hospice • Marie Curie Hospice Hampstead • Central London Community Healthcare NHS Trust's Pembridge Palliative Care In-patient Service (this service is currently suspended – patients who would have usually had support from this hospice or in this catchment area can access currently other hospice in patient units)

Ealing	• London North West University Healthcare NHS Trust (Meadow House Hospice)
Hammersmith & Fulham	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care In-patient Service (this service is currently suspended – patients who would have usually had support from this hospice or in this catchment area can access other hospice units) • St John's Hospice
Harrow	• St Luke's Hospice
Hillingdon	• Harlington Hospice (Michael Sobell House in-patient unit)
Hounslow	• London North West University Healthcare NHS Trust (Meadow House Hospice)
Kensington & Chelsea	• St John's Hospice • Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care In-patient Service (this service is currently suspended – patients who would have usually had support from this hospice or in this catchment area can access other hospice units)
Westminster	• St John's Hospice • Royal Trinity Hospice • Central London Community Healthcare NHS Trust's Pembridge Palliative Care In-patient Service (this service is currently suspended – patients who would have usually had support from this hospice or in this catchment area can access other hospice units)

In NW London, activity data from our current in-patient bed care providers shows us that our hospice in-patient beds (excluding Pembridge IPU but including spot purchased beds in lieu of its suspension) are on average 76% full. This means there is more capacity within hospices inpatient units that we could use to care for our patients in NW London if we used it better.

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 (see the full analysis).

In response to this engagement and as part of our continuous efforts to improve our hospice in-patient services bed capacity usage, a joint clinical audit of hospice in-patient admissions was conducted across all five hospices currently providing in-patient bed services to NW London.

The audit objective was to better understand the utilisation of our specialist hospice in-patient beds and to explore our hypotheses that some patients being admitted to these beds would have their palliative care needs better met within alternate care settings such as nursing homes or enhanced end-of-life beds. Understanding this information would also help determine current unmet demand for these enhanced end-of-life care beds.

The audit involved a review of 100 consecutive hospice admissions across five in-patient units in mid-January 2023. Of those 100 admissions, 24 cases had insufficient information to be included in this analysis, leaving a relevant sample population of 76 admissions.

Of the 76 sampled hospice inpatient admissions, 20 cases (26%) were determined to have had their needs met with alternative care such as nursing home care (14 cases) or enhanced end-of-life care beds (6 cases) if this second type of provision is available in the community. This audit demonstrated that 14.7 hospice in-patient beds could have been made available if these patients had been supported in alternate care settings. See section above (10.2a: Enhanced end-of-life care beds) for full details.

Outputs from travel mapping exercise completed for current hospice in-patient units across NW London

In-patient hospice unit 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 examined the travel times of small geographical areas at peak time across public transport and driving (see the full 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.

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

Why change is needed?

We expect the growth for NW London's in-patient bed use to be in line with the growth of 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.

We know, through our hospice inpatient unit admissions audit (see p70, results of a collaborative hospice inpatient bed audit), that our hospices are currently caring for some patients who do not need short term, intensive hospice in-patient bedded care.

We also know that the majority of people would prefer to die in their own home if they could. The model of care is proposing to increase the support to allow that to happen, be it in their own home or a nursing or care home enhanced care bed.

The introduction of enhanced end-of-life care beds will increase the overall number of beds available to NW London patients and these will be available to care for patients who need 24-hour care, but do not need the specialist palliative care support the hospice in-patient multidisciplinary team provide. Caring for these patients in enhanced end-of-life care home beds will also increase current hospices capacity for patients who need that specialised support.

We understand that our population healthcare needs can change over time, so it's important for us to regularly review and reassess our projections. While our analysis suggests that our current specialist hospice in-patient bed numbers should meet the needs of our population until 2031, we will continue monitoring utilisation rates and keeping an eye on factors such as population growth and healthcare trends. This way, we can make sure we can provide adequate care and make any necessary adjustments to meet the demands of our diverse communities in the future.

When we factor all this in, we believe that the current number of in-patient beds operating in NW London will meet NW London patient need for the specialist palliative care our hospices provide until 2031. We are therefore not recommending an increase to our specialist hospice in-patient bed provision at this time as part of the new model of care.

Although we are not recommending any changes to the number of hospice in-patient bed numbers that we purchase, this does not mean that in-patient bed services can continue as they are.

The new model of care proposal for hospice in-patient unit beds will deliver excellent care for all NW London residents irrespective of which borough they live in.

The recommended future model of care aims to provide highly specialised and comprehensive care, comfort, dignity and comprehensive symptom management for patients with life-limiting illnesses who have complex medical, psychological, emotional, and social needs.

Led by consultants in palliative care medicine and supported by a diverse multidisciplinary team, our hospice in-patient bed units will collaborate to deliver personalised and compassionate care.

The key elements of the service will include:

- **Location of services and setting of care**: Patient care is primarily provided within a hospice setting and goes beyond a typical clinical environment that you would find in a hospital. The homely atmosphere creates a serene and tranquil experience, ensuring comfort for all who use these services.
- **Accessing the service**: Patients are admitted to the hospices through referrals from healthcare professionals only, including GPs, adult community specialist palliative care teams, social care professionals, community nurses and other community services teams, as well as hospital teams. Self-referral is not supported. However, patients who make contact with the hospices to discuss hospice in-patient admission will be supported accordingly.
- **Length of stay**: It is important to note that the in-patient bed care unit is not intended to be a long-term care facility. Instead, it serves as a temporary place where patients can receive specialised intensive 24-hour care and support. The typical duration of stay is around two weeks (14 days), although this can vary based on individuals' needs, during which patients receive short-term, intensive support from the hospice specialist multidisciplinary care team. Patients who require these services have a high degree of medical or social complexity, where their needs cannot be met at home with their regular care team. Some patients may pass away in the hospice, while others may stabilise and return to their usual place of care or move to another care setting, such as a nursing home or enhanced end-of-life care beds. Once a patient's condition stabilises and if they are not actively dying (meaning someone is in the final stages of life and death is approaching very soon), the hospice team will often work closely with them, and those important to them,

to support transfer of their care such as returning home, moving to a care home for the first time or an enhanced end-of-life care bed, based on their evolving needs,

- **End-of-life care:** For some patients, the hospice unit may provide care until end-of-life, while others may experience symptom stabilisation and transition to a different care setting.
- **Hours of operation**: Services operate seven days a week, providing 24-hour care for patients on the in-patient bedded unit. Routine (planned) and emergency (unplanned) admissions are supported from Monday to Sunday, 9am to 5pm, making sure there is continuous access to care[8].

The admission and discharge criteria for these beds

Who is eligible to be referred:
Hospice in-patient unit bed care services are designed to cater for the needs of adults aged 18 and above who have complex life-limiting illness. These patients are usually no longer receiving treatment to try to cure their illness or disease. They may have various conditions such as cancer and other non-cancer diagnoses, including neurological disorders, advanced dementia, respiratory disease, heart failure, or organ failure. This also includes patients who are approaching the end-of-life due to age, particularly those over 85 years old. The hospice offers a wide range of care and support options within the in-patient bed care unit, accommodating the diverse needs of patients at any stage following their diagnosis of a life-limiting illness.

The criteria below have been developed in collaboration with all stakeholders who provide in-patient hospice bed care in NW London currently. There is a recognition not all admissions will fit a specific criterion due to the unique nature of circumstance of the resident and a multi-disciplinary team review may take place to ensure the most appropriate specialist palliative care support is provided on a case by case basis.

Hospice in-patient bed care admission is based on patients' needs being unmet by all other services available and will offer various admission categories and criteria to address specific patient needs which include:

- **Complex case admission**: Assessment, case review, and symptom control for patients with complex needs. This category admits patients for typically up to two weeks when their symptoms become unmanageable at home. Psychological support is available, especially during crisis situations.
- **Specialist rehabilitation admission**: Rehabilitation for patients needing specialist physical, psychological, and spiritual support after palliative care treatments. Collaborative goal-setting supports the patient's recovery and overall well-being.
- **Specialist respite care admission**: Short-term in-patient stays for patients with very complex specialist palliative care needs to support their carers who require a break and where other community respite options are not appropriate. This category benefits patients with highly complex needs or

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[8] Typically, hospices run a reduced staffing structure at the weekend and accommodate planned and unplanned admissions as much as possible on a case-by-case basis.

technology dependence. Respite care admissions typically last one to two weeks, with a maximum of two planned respite breaks allowed within a twelve-month period.

- **Specialist end-of-life care admission**: Specialist end-of-life terminal care for patients in the advanced stages of a terminal illness. Admissions typically last two to three weeks, with a focus on end-of-life care. This may be planned or urgent, depending on the patient's condition.

Summary: what will be different

The new model of care will deliver two notable changes for hospice in-patient bed care services in NW London:

- **Expanded admission acceptance:** By extending admissions for routine and planned care to seven days a week during core hours of 9am to 5pm, we are addressing the national ambition of improving access to care for patients with life-limiting illnesses. This change allows both planned and unplanned admissions to occur on any day. It makes sure that patients can promptly access comprehensive and specialised care. Removing the limitations of admission to specific days of the week eliminates unnecessary delays and enables individuals to receive the care they need when they need it.
- **Revised and standardised hospice in-patient bed admission criteria:** We have updated and standardised the criteria for admitting patients to hospice in-patient bed care units across all Hospices in NW London. By implementing consistent clear admission criteria, we make sure that hospice beds across all of our boroughs are allocated to patients with complex care needs that require this consultant-led multidisciplinary team support. These criteria also support the discharge of patients on the continuing healthcare fast track and those who are routinely dying in hospitals. It's important to note that these changes do not compromise the care of complex patients requiring this support, as hospices will robustly triage their referrals and manage any waiting lists. By streamlining the flow within the system and addressing urgent care needs promptly, we optimise resource management and potentially increase our hospice bed capacity, enhancing the overall quality of care we provide.

See section 7.7 Issue seven: How financially sustainable is community-based specialist palliative care now and in future for further information about the issues raised by the fact that the non-NHS hospice sector is reliant on a combination of NHS and non-NHS funding, with the latter requiring substantial fund raising.

10.3 Service area 3: Hospice out-patient services, hospice day care services, and community-based specialist palliative care well-being services (including lymphoedema, psychological and bereavement support services)

In this service area, we describe three service types, each comprising various specialised services. These services are primarily provided at the hospice but do not require an overnight stay. They cater not only to the patients but also extend support to their families, caregivers, and friends to promote overall well-being.

The three service types in this third service area are:

a) Hospice out-patient services
b) Hospice day care services
c) Community-based specialist palliative care well-being services (including psychological and bereavement support for patients and their families/ carers)

These specialised services and programmes cater to individuals with life-limiting illnesses who don't require 24-hour in-patient care. They offer comprehensive care, comfort, and social interaction during the day, enabling patients to return home or to other care settings at night.

The services are provided in the main by hospice specialist palliative care multidisciplinary teams and volunteers. They are largely delivered at the hospice but may also be offered through virtual means, leveraging technological advancements to align with patient preferences and optimise workforce productivity.

NHS NW London is responsible for funding transport to a range of community services including these. Consistency of patient transport is being addressed via a NW London programme addressing ‘Non-Emergency Patient Transport (NEPTs)’.

10.3a Hospice out-patient services

Hospice out-patient services provide medical and supportive care to individuals with life-limiting illnesses without requiring them to stay in the hospice or visit a hospital. Patients receive care during the day and can return home afterward, maintaining a sense of normalcy and familiarity.

The out-patient appointments or clinics offer one-on-one care from a team of palliative care experts, including doctors, nurses, therapists, psychologists, spiritual advisors, and social workers. These clinics focus on managing symptoms, relieving pain, and ensuring patients are as comfortable as possible during their advanced illness.

The services are tailored to meet the unique needs of each patient, encompassing medication review, diagnostic tests, pain management, care planning, and rehabilitation. To access these services, patients need to have an advanced life-limiting illness and may be referred by a healthcare professional or self-refer.

Hospices often assist patients in arranging transportation to reach the hospice services location, ensuring accessibility for all.

10.3b Hospice day care services

Hospice day care services aim to provide care and support during the daytime for patients at the hospice, offering respite for their caregivers and families who need to take a break from providing constant supervision and support. These services encompass various social activities, therapeutic programs, and community events to enhance the overall well-being of patients.

Additionally, day care services provide practical assistance, information, and advice to both patients and their families or caregivers. This includes welfare checks, financial advice, guidance on legal matters, support with making funeral arrangements, and connecting patients and families to other community resources that can be helpful to them.

The services are often supported by hospice volunteers, who play a crucial role in creating a warm and compassionate environment.

10.3c Community-based specialist palliative care well-being services (including psychological and bereavement support)

Well-being services are designed to improve a person's overall health, happiness, and quality of life throughout their palliative care journey. These services focus on physical, emotional, social, and mental well-being, offering various activities, therapies, and support to promote positive outcomes and fulfilment.

Complementary therapies are one aspect of well-being services and include non-invasive supportive approaches that work alongside conventional medical treatments. These therapies provide additional comfort, relaxation, and symptom relief, addressing physical, emotional, and psychological needs.

Common complementary therapies in palliative care may include massage therapy, music therapy, art therapy, mindfulness and meditation, aromatherapy, yoga, and Reiki.

These services not are not funded by NHS NW London as they are not core specialist palliative care services as set out in the national adult specification for palliative and end-of-life care and supporting commissioning framework documents.

Spiritual support is another vital component of well-being services, focusing on helping patients explore and find meaning, comfort, and peace in their spiritual beliefs and practices during their palliative care journey and beyond. It allows patients to connect with their inner beliefs, values, and sense of purpose, fostering spiritual well-being and coping with existential questions.

Chaplains, spiritual counsellors, or trained professionals engage in conversations about faith, purpose, and connection to something greater than oneself, offering spiritual guidance and support tailored to the individual's beliefs and preferences.

Emotional support is essential in helping patients and their families cope with the emotional challenges, fears, and uncertainties that arise from the diagnosis and progression of a life-limiting condition. Expert professionals and trained volunteers provide a compassionate presence, active listening, and validation of feelings, creating a safe space for patients and families to express their emotions and concerns. This ongoing emotional support addresses needs at different stages of the illness, treatment, and end-of-life care, promoting a sense of comfort and understanding.

Psychological support is also a crucial aspect of well-being services, addressing the mental and emotional well-being of patients and their families through evidence-based interventions. Trained mental health professionals, such as psychologists and counsellors, conduct assessments and offer counselling and psychotherapy to enhance coping strategies and improve resilience. Psychological support aims to promote better psychological adjustment and overall well-being during palliative care, addressing specific mental health concerns. These services are available to patients, their families, caregivers, and loved ones during advanced life-limiting illness, impending death, and the grieving process, providing essential emotional and practical assistance during a challenging time.

Bereavement support is provided to individuals who have lost a loved one receiving care under the hospice or community-based palliative care services. It helps individuals navigate the grieving process and adjust to life after the death of their loved one. Bereavement support includes individual counselling, support groups, and resources tailored to address the unique needs and emotions experienced by individuals during the bereavement period. These services provide a safe and supportive space for individuals to express their grief, share memories of the deceased, and find ways to cope with the loss, offering essential support during the grieving process and beyond.

The current provision of hospice out-patient, hospice day care, and community-based specialist palliative care well-being services in NW London

The landscape of these hospice out-patient, day care, and well-being services in NW London is complex. The current provision of these services in NW London varies across different provider due to our hospices' individual charitable statuses and independence from the NHS, and the fact that the NHS only partially funds, or in some cases, does not fund these services. For example, day care services and complementary services.

This is the same picture nationally and regionally. This leads to hospices relying significantly on charitable funding to provide these services. However, the independence of these hospices in regards to these and other services is valuable, as it allows them to tailor and enhance services to best meet the unique needs of their local communities and pilot new services more readily than the NHS.

As some of these services are fully funded by independent hospice charitable funds, it can lead to variations in service levels and access. The lack of a common core offer for some services results in inequitable care and outcomes for some patients across NW London.

Table below: Current hospice out-patient, day care and well-being provision (that is funded by NHS NW London and not funded)
(Click here to view a larger version of the table)

	Service offer	St Luke's Hospice	Harlington Hospice	St John's Hospice	Marie Curie Hospice Hampstead	Meadow House Hospice LNWH	Royal Trinity Hospice	Pembridge CLCH
Outpatient clinics / services	Outpatient clinics and therapies (1:1) by clinicians with specialist multidisciplinary team members (e.g. doctors, nurses, allied health professionals, psychologists, spiritual advisors, social workers) for assessment intervention e.g. pain management and medication management; infusions, diagnostics, rehabilitation	🟢	🟢	🟢	🟢	🟡 No medical or nurse led clinics	🟢	🟢
	Lymphoedema services	N/A	🟢	🟢	N/A	🟢	N/A	N/A
	Multidisciplinary team group clinics e.g. exercise classes, fatigue management, mindfulness	🟢	🟢	🟢	🟢	🔴	🟢	🟢
Day care services	Social and therapeutic activities e.g. art and music therapy, volunteer programmes (not funded by NHS NW London)	🟢	🟢	🟢	🟢	🔴	🟢	🟢
	Practical support and advice e.g. welfare, wills, finance (not funded by NHS NW London)	🟢	🟢	🟢	🟢	🟢	🟢	🟢
Wellbeing services	Emotional & psychological support (group or 1:1)	🟢	🟢	🟢	🟢	🟢	🟢	🟢
	Bereavement support (counselling group or 1:1)	🟢	🟢	🟢	🟢	🟢	🟢	🟢
	Spiritual support (1:1 or group)	🟢	🟢	🟢	🟢	🟢	🟢	🟢
	Complementary therapies e.g. acupuncture, aromatherapy massage, reiki, reflexology (not funded by NHS NW London)	🟢	🟢	🟢	🟢	Curretly suspended	🟢	🟢

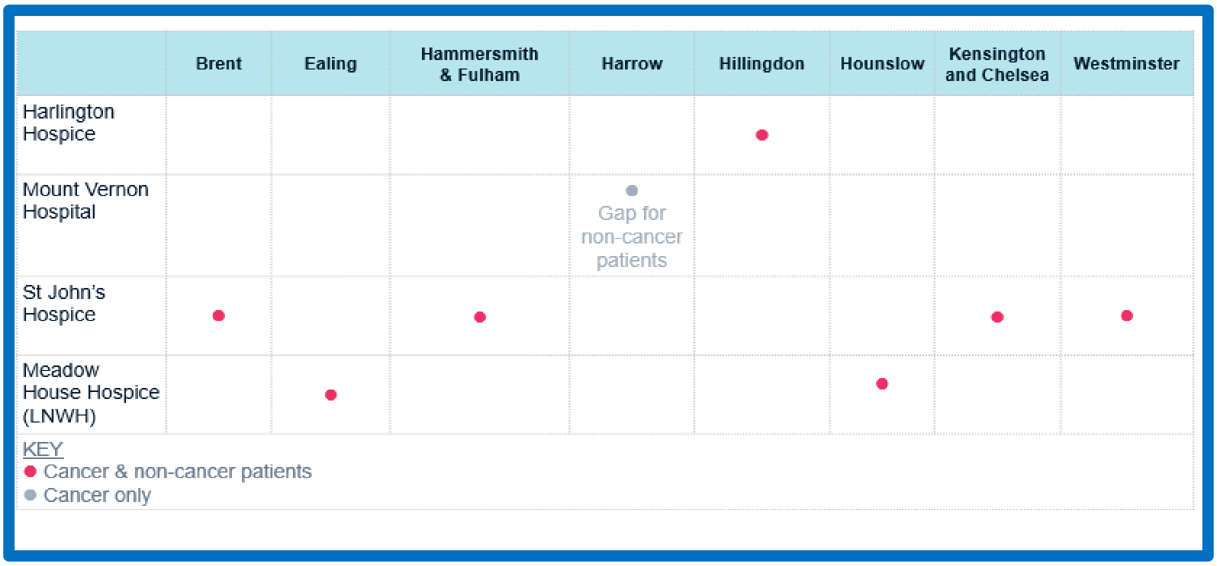
Key

🟢	Available
🟡	Partially available
🔴	Not available
▨	Not funded by NHS NW London
N/A	Not available from provider and not commissioned

For more comprehensive information on these types of services offered by each provider please see appendix G

Current lymphoedema out-patient service provision for NW London (for cancer and non-cancer patients)

The table below shows that there is currently a gap in out-patient lymphoedema service provision for non-cancer lymphoedema patients in Harrow.



	Brent	Ealing	Hammersmith & Fulham	Harrow	Hillingdon	Hounslow	Kensington and Chelsea	Westminster
Harlington Hospice					🔴			
Mount Vernon Hospital				⚪ Gap for non-cancer patients				
St John's Hospice	🔴		🔴				🔴	🔴
Meadow House Hospice (LNWH)		🔴				🔴		

KEY
- 🔴 Cancer & non-cancer patients
- ⚪ Cancer only

Why is change needed

Each hospice offers unique and invaluable hospice out-patient, day care and well-being services to their communities The landscape is complex and there is limited commonality in naming and grouping of services across providers.

Where NHS NW London does not fund services in this service area, it is not within our gift to mandate a common core offer for these services. We would also not want to risk reducing innovation and the current high level of care and support being offered via our charitable hospice partners.

Where we do fund services the new model of care working group recognised the benefit of aiming to standardise and level these up as much as possible. However, given the current financial pressures for NHS NW London there is not likely to be any new investment to support this.

The key issues and drivers for change include variation in services, inequitable access, and lack of cultural sensitivity. While some residents receive important and valued services, others lack access to quality care.

Where NHS NW London does fund services, there is notable variation that requires levelling-up. The new model of care aims to establish a more equitable level of service and availability across NW London, promoting fairness and enhancing services with charitable funding. The change is needed to raise up the level of these boroughs and types of service:

- For the boroughs of Ealing and Hounslow, raising up the level of hospice out-patient services is required.
- For the borough of Harrow, expansion of lymphoedema provision is required to support non-cancer related lymphoedema patients to receive this care more equitably.
- The introduction of a common offer, and more robust pathway for psychological and bereavement support for all NW London boroughs to support more people and have improved patient outcomes.

Proposed changes for services within the new model of care

Under the new model of care, existing hospice out-patient services will remain with efforts made to level-up care in areas like Ealing and Hounslow where there is a gap in hospice out-patient services.

The introduction of a common core service for lymphoedema services based on the national lymphoedema specification will allow us to deliver consistent and equitable care across all areas, including Harrow, for both cancer and non-cancer patients. This minimum common core offer will include:

- Specialist support to care for individuals with chronic upper and lower limb lymphoedema, including support and education to help patients to self-manage their symptoms.

- Eligibility and admission criteria that welcomes all patients with primary and secondary lymphoedema, regardless of the underlying cause.
- Referral system that allows patients to be referred to the service by various healthcare professionals involved in their care. Self-referral will be encouraged, allowing individuals to take an active role in seeking the care they need.
- Qualified service team, consisting of highly qualified therapists who specialise in lymphoedema management. Staff will have a degree-level qualification and be well-versed in holistic management strategies, including rehabilitation, exercise and wound management.
- Operational hours of weekdays from 9am to 5pm. To support continuity of care, there will be mechanisms in place to address urgent needs outside of these hours.
- Triage system where patients are prioritised based on their needs and the nature of their lymphoedema. Patients requiring immediate attention will receive prompt care.
- Wide range of core services covering a variety of comprehensive care approaches. These will include holistic assessments, personalised care planning and treatment, lymphatic drainage, skin care, compression therapy, exercise and weight management interventions, and education for self-management. Staff will also refer and signpost patients to other services as needed.

The new model also proposes introducing a common core offer for psychological support for patients and bereavement support services for their family, carers and those important to the patient within our community-based specialist palliative care provision for all of NW London. The key principles of this will include:

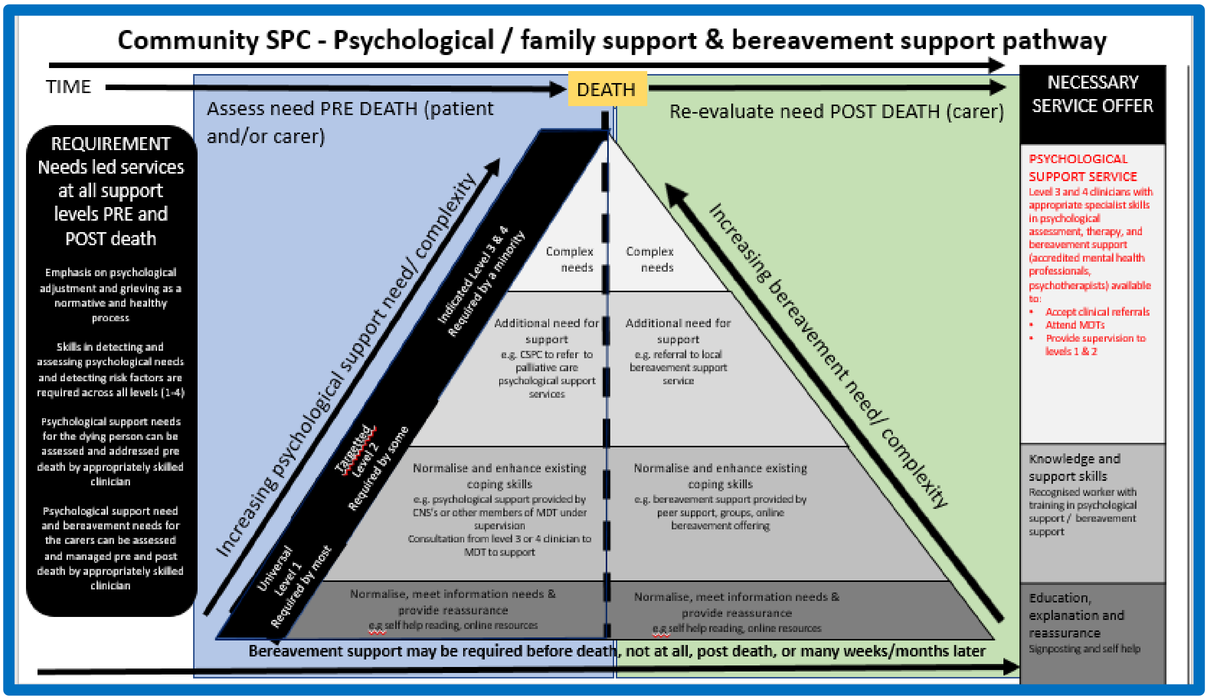
- The acknowledgement that psychological adjustment and grief in the palliative care phase is healthy and normal, as is grieving after death.
- A robust assessment process for more complex needs in both the palliative care phase and after death.
- Personalised assessment and needs led care.
- A range of evidenced-based support and therapeutic support which are based on assessment and need.
- Integrating both psychological and bereavement services to make sure patients, families and those important to them are supported during the different stages of the end-of-life.
- Palliative psychological family services, bereavement services and social support services will be closely aligned with a clear pathway. This will help make sure people are seen by the best service for them at that time, allowing for stepping up or stepping down levels of support flowing from the clear assessment process.
- Pre-bereavement support such as signposting advice for funeral costs and benefit checks (as raised/ highlighted during our engagement on the model of care).

The support available will include one-to-one counselling and group sessions provided by multidisciplinary psychosocial teams drawn from psychology, psychotherapy, counsellors, social workers, support workers and complementary therapists with appropriate training and knowledge of palliative care and bereavement.

Who is eligible to be referred

Eligibility for these psychological support and bereavement support services will be driven by need with a focus on patients who are in the palliative and last stage of life phases and family and carers during both the palliative phase and after bereavement. Need will be established through a holistic assessment by the community-based specialist palliative care psychological and bereavement practitioners within the hospice specialist palliative multidisciplinary team.

A framework to support the understanding of the above core common offer information (please click here to view a larger version of the diagram)



Source: Developed and signed off within the psychological support and bereavement subgroup of the Hillingdon Health and Care Partners

The introduction of the model of care will lead to more consistent, personalised, and flexible support with a clear pathway and robust assessment process. The goal is to provide inclusive, culturally sensitive care to all residents of NW London, ensuring that expert staff with appropriate training can provide a wide range of care and support at the right time.

Overall, the proposed changes as laid out in this service area aim to enhance the quality of care and support for patients and their families, promoting better well-being and outcomes throughout the palliative care journey.

The new model seeks to address the current gaps and variation in service provision, improve access to services, and create a more standardized approach to care while respecting the individuality and diversity of each hospice's community. By implementing these changes, NW London can offer comprehensive, holistic, and equitable care for individuals with life-limiting illnesses and their families.

See appendix G to view a table detailing current hospice out-patient, day care and well-being provision.

11. The key enablers that will help us deliver the new model of care

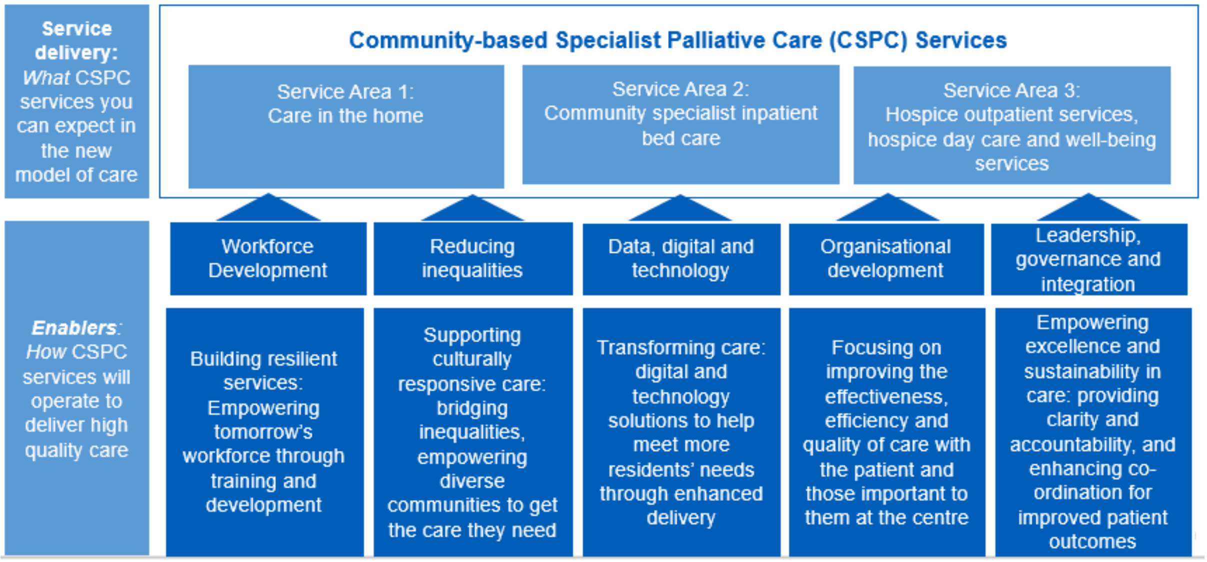
A key feature in the feedback we received from local people was the need to make sure we put in place effective ways of working and the systems and processes that are needed to support the delivery of high quality palliative and end-of-life care.

There was a particular emphasis on the need to reduce health inequalities and have a palliative care workforce (generalist and specialist) that is both sustainable and understands the cultural and faith requirements of our diverse communities.

We have identified five key enablers that we will need to develop and put in place to support the successful implementation and delivery of our new model of care and achieve the improvements in care we aim to deliver:

- Workforce development
- Reducing inequalities
- Data, digital and technology
- Organisational development
- Leadership, governance and integration

Diagram showing the enablers we need to support delivery of the model of care (please click here to view a larger version of the diagram)



Service delivery: *What* CSPC services you can expect in the new model of care

Community-based Specialist Palliative Care (CSPC) Services

Service Area 1: Care in the home

Service Area 2: Community specialist inpatient bed care

Service Area 3: Hospice outpatient services, hospice day care and well-being services

***Enablers**: How* CSPC services will operate to deliver high quality care

Workforce Development: Building resilient services: Empowering tomorrow's workforce through training and development

Reducing inequalities: Supporting culturally responsive care: bridging inequalities, empowering diverse communities to get the care they need

Data, digital and technology: Transforming care: digital and technology solutions to help meet more residents' needs through enhanced delivery

Organisational development: Focusing on improving the effectiveness, efficiency and quality of care with the patient and those important to them at the centre

Leadership, governance and integration: Empowering excellence and sustainability in care: providing clarity and accountability, and enhancing co-ordination for improved patient outcomes

Enablers typically refer to essential components or factors that facilitate or support the successful implementation of a project, an initiative or process. Some people might call enablers building blocks, cross cutting changes or the infrastructure necessary for achieving the desired outcome. The aim is to remove barriers, improving efficiency, and supporting overall success. They serve as fundamental pieces, that have impact across different aspects of the project and organisation and are supportive in the functioning of the system. The important thing is that they address ways of working rather than them being new services.

While enablers may not be considered as direct patient care, they provide the essential support mechanisms needed for the workforce and organisations to deliver care effectively. By identifying and leveraging enablers, projects and programmes can overcome challenges and maximise their impact on improving patient outcomes and achieving the intended goals.

The five supporting enablers listed above and their associated strategies and activity are needed to make sure we can deliver the future model of care. They are not options which require long-listing, short-listing or public consultation, but rather consistently underpin all elements of future working arrangements for the new model of care.

Developing a detailed picture of what each of these enablers means and how that translates into the offer to patients has not been a part of the model of care working group's remit to date. However, there have been some productive discussions about what could be included. We anticipate building further detail for each of these enablers at a later stage through collaborative task and finish groups as part of the model of care implementation planning.

11.1 Workforce development to address the need for a pipeline of skilled workers into the future

High quality palliative and end-of-life care services require multidisciplinary teams to work collaboratively across all care settings, with sufficient workforce with the appropriate skill mix, supported by high quality education, training and professional development.[9]

Our workforce development strategy will need to align with the developing NW London health and care strategy and is seen as a priority that will need to be addressed as a matter of urgency. However, we need to recognise that some issues such as workforce recruitment and retention are long-term national structural problems and there are no quick fixes. There is an opportunity for our non NHS providers to work alongside our wider NHS approach.

This enabler has two parts. Firstly, to ensure that there is a workforce plan in place and the right workforce to support patients with community-based specialist palliative and end-of-life care needs. And secondly, that there are staff across all settings of care who have the requisite skills, from the specialists to the generalists supporting people with palliative and end-of-life care needs as part of their wider roles such as GPs, community nursing staff and those working in care homes. It is important that

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[9] Palliative and End-of-life Care, Statutory Guidance for Integrated Care Boards (ICBs) NHS England, 29 September 2022.

staff delivering care have access to training, including in the identification of people in the last year of life, and in difficult conversations and personalised care planning.

It is also important that staff are supported to attend appropriate training and development, and to identify their leaning, training and education needs. Workforce planning, resilience, well-being and improving training and education for all staff working in palliative and end-of-life care, not just specialist palliative care, were highlighted within our engagement work and in the new model of care working group discussions.

A community-based specialist palliative care workforce development strategy will be jointly developed across all charitable and NHS organisations to support workforce development and service delivery. Sharing of good practice within this specialism, meaning different providers collaborating on different areas, the aim will be to develop a provider collaborative that will jointly work together on improvement initiatives. This will seek to address recruitment, retention and shortage of key workforce including community nursing specialist and palliative care consultants. It will also support staff to work at the top of their competencies and bands, and foster innovation.

Some examples of strategies that can be used to support this work include:

- Creating flexible career pathways across all the organisations within the NW London Integrated Care System.
- Development of hospice provider collaboration to explore specific workforce planning and efficiencies across their organisations.
- Developing an inclusive culture and practices.
- Improving staff wellbeing and providing better support.
- Doing things differently - looking at hard to recruit roles and redesigning models of care to make services and roles better for staff and patients. Ongoing professional development by making sure effective education and training programmes are in place (face to face and virtually) for continuous learning and skill enhancement to support the sector to deliver future ways of providing care, new roles and advancement opportunities, new apprenticeships and career pathways through the NW London health and care skills academy.
- Increased utilisation of staff competencies and optimisation of clinical time through role expansion that supports staff to work to the top of their competency bands/ roles
- Embedding use of technology into care delivery to augment care and optimise productively. For example, remote monitoring, virtual consolations using tablets, electronic health records for efficient documentation, and mobile applications for improved communication and information sharing.

The workforce development enabler is integral to equipping healthcare professionals and support staff with the necessary skills and knowledge to deliver high-quality palliative care. By providing specialised training programmes encompassing pain management, symptom control, communication, and emotional support, we can enhance the competency of the workforce.

Cultivating interdisciplinary collaboration among doctors, nurses, social workers, psychologists, and chaplains will facilitate a holistic approach to patient care. A skilled and collaborative workforce will not only improve patient outcomes but also contribute to more sustainable and efficient care delivery.

Whilst we are engaging on this model of care we can continue to work with providers and the NW London workforce team to develop more concrete and time-lined plans to ensure the identified work on recruitment/retention and the current capacity gaps are progressed to support delivery timescales.

11.2 Reducing inequalities in access, outcomes and experience

We know that we need to do to more to reach all of our diverse communities as some are not using community-based specialist palliative care. Our engagement found there was a lack of awareness in certain communities and that there was a need to take into account the diverse cultural and faith practices and beliefs of NW London residents.

Our March 2022 engagement report highlighted two key areas of focus for reducing health inequalities:

- We should look at ways of tackling the widening health inequalities for people who require palliative and end of life care and support services, driven by the increased costs of living for people in areas of high deprivation.
- Attention should be given to isolated people, those with family outside the country or in different regions, elderly couples that are physically or mentally unable to care for each other, the large number of disabled people that require specialist care and those who experience homelessness.

Actions we are taking based on these areas of focus include:

- Building an end of life care dashboard that focuses on areas of deprivation. This will help our providers to not only improve access by targeting key geographies and areas of deprivation in NW London, but also to track outcomes for patients in areas of deprivation and monitor which interventions cause the biggest impacts in outcomes.
- We conducted a literature review of people with learning disabilities and those who experienced homeless and will be working with our outreach teams to monitor and review successful implementation of the key recommendations within the new model of care. In particular, this may include but is not limited to:
    - The number of people living with homelessness approached by our outreach teams.
    - The care plans developed for people living with homelessness.
    - The number of hostels receiving remote or virtual support.
    - The training received by hospice/provider staff and specialist palliative care settings to support people living with homelessness (especially using the homeless palliative care toolkit).

In addition, we believe that implementation of the proposed model of care will have a positive effect in reducing health inequalities in the following ways:

Equitable access

The model prioritises equitable access to specialist palliative care services in the community for every individual, irrespective of their socio-economic status, ethnicity, culture, or the borough they reside in through establishing community-based palliative care services in areas where these services are currently not provided (e.g. Hospice at home, 24/7 telephone advice line for known and unknown patients and outpatient services) to ensure that more people get specialised care reducing the gap between those patients who currently receive these and those that do not. The almost doubling of bed capacity through the introduction of enhanced end-of-life care beds is likely to bring a range of new beds to more people and closer to their home.

Culturally competent care

There is recognition of the importance of cultural competency and providing personalised care that respects and accommodates the diverse cultural backgrounds of patients and their families/ carers/ those important to them, through supporting providers to develop a cultural competency framework for NW London CSPC providers to implement. This framework will include appropriate training for staff to deliver culturally competent care to address the unique needs and beliefs of each patient.

Care co-ordination

The model recognises the important of developing robust care coordination mechanisms that ensure seamless access to services for individuals with specialist palliative care needs. This entails fostering collaboration and improved partnership working at place between generalist palliative care providers (primary care, social care and other community healthcare teams) and specialist palliative care teams (in community and in hospital), but also within community specialist palliative care teams themselves in the first instance. The model sets out ambitions for boroughs to develop local arrangements for single points of contact/ access for these services and internal care co-ordination approaches for example key workers/ internal co-ordination functions. It also sets out the ambition for more integrated working across Integration neighbourhood teams locally to support increased MDT working.

Outreach and engagement

Ongoing engagement by the ICB and providers to actively engage with underserved populations, making an effort to reach those who might not seek or understand palliative care nor consider their future care preferences on their own. This may involve outreach programs (which will take account of the fact that some residents may not have access to the internet and will require non-digital communication), partnerships with community organisations and the provision of more home-based care services, as well as communications and partnership working to increase the use of advance care planning through the Universal Care Plan (https://ucp.onelondon.online/).

Research and data collection

Collect data on health disparities within specialist palliative care providers in NW London to identify and address gaps in service provision. Informed by research, targeted interventions and policies can be developed amongst providers to reduce disparities in care delivery and outcomes. NW London ICB is developing the end of life specific dashboard (referenced in the actions we are talking above) which will include demographic and health inequalities data metrics, alongside developing a standard data set for CSPC providers to report on that includes these key metrics, which will feed the dashboard.

Education and awareness
All providers are committed to raising public awareness and providing education and training about palliative care for health and care professionals and within communities across NW London. By increasing awareness, more individuals can access these services and benefit from them, addressing disparities in care utilisation.

Patient choice and involvement in care
The model aims to enhance health literacy among residents by empowering them with a better understanding of palliative care and their end of life options through the promotion of advance care planning. This will enable patients to make informed decisions about their care and reduce disparities caused by a lack of information or opportunity and to have their wishes made known and shared with the health and social care system (for example via London's digital Universal Care Plan or UCP)

Outcomes and experience
We will work with our residents and providers to develop improved methods of capturing patient, family and carer experiences and outcomes to inform the development and operation of services under the new model of care. This will be addressed within the proposed task and finish groups related to the implementation of the new model of care, as well as our future engagement plans.

11.3 Data, digital and technology to support future service planning

Embracing data, digital tools, and technology can significantly enhance the sustainability, effectiveness, and efficiency of our community-based specialist palliative care services. Linking into NHS NW London health and care strategy there is a recognition amongst all providers that we need to make more use of new and innovative technologies to improve and support clinical decision making.

Some potential strategies could include a commitment to greater use of remote monitoring technologies and telehealth services, which can proactively manage patient symptoms, leading to better patient outcomes and reducing the burden on acute care settings.

This could include:

- Working together to support coding and counting activity in the same way so we can understand differences in the care services provided by our various providers in more easily comparable ways.
- Supporting implementation of shared records and standardisation of clinical systems in as much as possible, so all clinicians supporting the health and care of an individual can see their information across multiple care settings. For example, implementing electronic health records and facilitating and embedding use of the health information exchange and London care record

can support streamlining the data sharing among healthcare providers and sectors. This will promote care coordination, reduce duplication of efforts and prevent patients having to repeat themselves at each appointment. Use of the Universal Care Plan (UCP) to support recording and sharing of patient preferences and care plans will improve this further

- Creating new ways to provide care using advances in technology through, for example, virtual wards and home remote monitoring.
- Developing a single dataset of timely, detailed health and care information, that can help clinicians provide the right care and support for patients.
- Developing systems to provide a NW London wide overview and management of demand, capacity and patient flows across hospitals and primary care services.
- Automating advice and guidance from clinical specialists to support GPs with referrals.

11.4 Organisational development to support working together differently

Organisational development is vital for creating an environment that supports the effective implementation of the new model of care. Some suggested strategies that could be explored by the enabler working groups could include more emphasis on adopting a patient-centred approach which will empower patients and their families in care planning, fostering a sense of ownership and improved decision-making.

Continuous quality improvement initiatives could also help to drive efficiency and streamline processes, leading to more effective and sustainable care.

Developing more transparent communication within the NW London ICS will help make sure that feedback from staff, patients, and families is valued, allowing for necessary adjustments and ultimately supporting the overall aim of improving patient outcomes and experience.

Additionally, actively recruiting and retaining a diverse workforce that reflects the cultural diversity of the community being served is important This includes promoting inclusivity in hiring practices and creating an environment that values and respects cultural differences.

11.5 Leadership, governance and integration

Leadership

Moving forward good leadership, integration and governance will be key if we are to deliver the new model of care and associated service and organisational development that is needed. We will need to build on the excellent leadership already shown by all providers as we have carried out this review, to further support:

- Strengthening collaboration and partnership working internally within the provider organisations and the wider care system partners to make sure that patients are at the centre of care delivery and co-design of services.

- Establishing strong governance structures to oversee and ensure the delivery of high-quality palliative care services.
- Providing leadership that fosters a culture of excellence, compassion, and continuous improvement.

Governance

Clearer expectations of ways of working between organisations in any given geography depend on robust clinical and organisational governance. As much as patients want to know who to contact, it is critical that other partners also know that line of accountability. Governance does not take away from the need to work flexibly and collaboratively across organisational boundaries but rather provides the safety nets for certainty on reporting lines and what happens when things do not go as planned.

We heard that patients and their families recognise that multiple providers will work together to meet the different needs that people, especially those with complex needs, often have. This can sometimes mean that it is unclear who is ultimately accountable. A single provider is not necessarily the answer, but we need to ensure that different providers work together to enable singular and clear accountability, especially if something is not going right. This can take the form of agreements between organisational providers such as the sharing of quality information, or could be regular forums to jointly manage shared cases.

Integration

Integration is both a cultural change and a major practical difference in how services work together. It includes:

- Reducing boundaries between organisations by fostering a ‘one team’ ethos.
- Reducing handoffs and the need for people to tell their story repeatedly.
- Coordination functions that remove the need for patients and carers to act as coordinators, and also free up our more specialist staff.
- Multidisciplinary teams and meetings as a way of working to plan with residents for theirs care needs across community-based specialist palliative care services in the first instance, as well as the wider health and care system in the community and acute hospitals.
- Integration across NW London and the community-based specialist palliative care and hospice sector through regular sharing forums. Facilitating improved information sharing between teams, organisation and sectors through use of shared care records where possible, including electronic patient records, the health information exchange (London Care Record) and the London Universal Care Plan (UCP).
- Fostering collaborative care models such as multidisciplinary teams within organisations and across organisations, working together to provide comprehensive and holistic care. This may be through encouraging regular team meetings, multidisciplinary ward rounds across community-based specialist palliative care services and wider system partners, to support shared decision-making, optimising the use of the specialist workforce and enhancing patient outcomes.

- Emphasising effective communication and care coordination among the healthcare providers involved in palliative care. Implementing tools and platforms that facilitate seamless information sharing, care planning, and follow-up.
- Creating platforms for staff members to share their experiences, ideas, and best practices with their colleagues and encouraging regular learning forums, case discussions, and peer mentoring to promote collaboration and knowledge exchange.

Through collaborative efforts and the careful consideration and development of strategies within the model of care implementation planning and task and finish groups focused on enablers of the new model of care, we can create a robust framework for supporting the successful delivery of the NW London community-based specialist palliative care services new model of care. By embracing these enablers laid out in model of care for its successful delivery, we aspire to improve patient outcomes, enhance care coordination, address workforce challenges, promote integration, and deliver value for money, all in line with the overarching goals of the new care model.

The next steps for this work is to scope and define the various task and finish groups for each of the enablers, supported by NW London ICS expert leads.

How community-based specialist palliative care providers can work with Integrated Neighbourhood Teams (INTs) to support more integrated and co-ordinated care at the local borough level:

We have heard through our engagement about the importance of joined up, integrated care for our residents. Through the development of this model of care we have engaged with key stakeholders to understand how to support delivering this. Integrated Neighbourhood Teams (INTs) can provide this joined up way of working. INTs are viewed as a delivery mechanism, aiming to unite the healthcare system to collectively assume responsibility for the population. They are expected to foster a culture of collaboration, problem-solving, and trust-building among primary care, other stakeholders, and communities, ultimately coordinating multi-disciplinary care as patients' needs change.

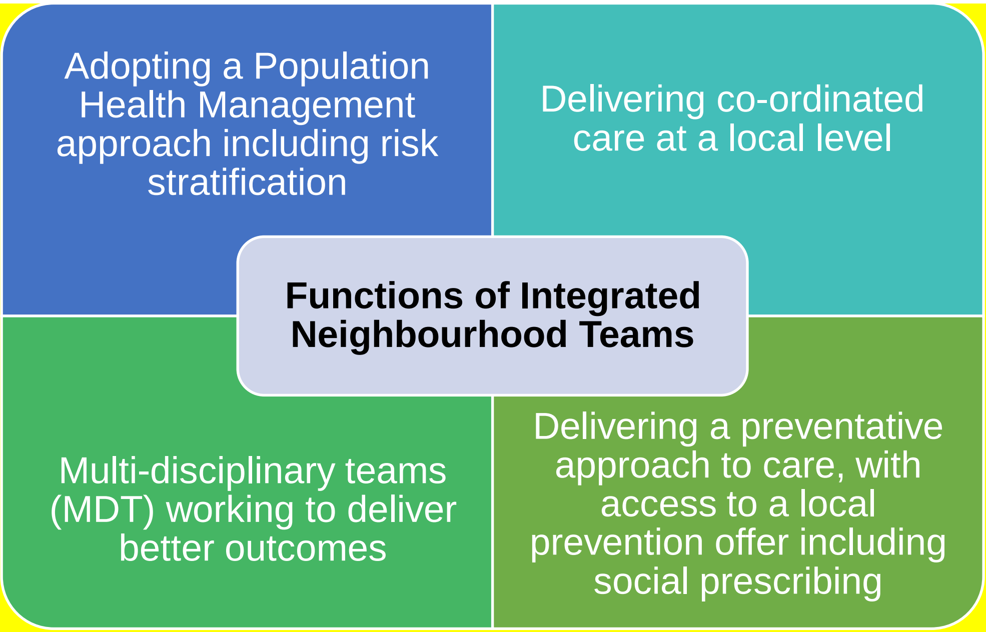
NW London ICB are currently in the process of developing a plan to roll out INTs across all eight NW London boroughs by April 2025.

Integrated neighbourhoods (INs) bring together multi-disciplinary professionals from different organisations across health and care services, such as wider primary care and community and social care teams around defined geographical populations, putting people at the centre of the care they receive. With the aim to deliver more joined up preventative care at a neighbourhood level. Community based specialist palliative care teams would be an important member of the multi-disciplinary professionals.

In NW London, we have a wide range of health and social care services providing high-quality services as individual organisations. We know that when working in a more integrated way together, they have an even greater impact on health, wellbeing, quality of care delivery and a better experience across these interfaces for the people working in our services.

INTs will be responsible for:

- Providing more proactive, personalised care with support from a multidisciplinary team of professionals to people with more complex needs, including, but not limited to, those with multiple long-term conditions.
- Helping people to stay well for longer as part of a more ambitious and joined-up approach to prevention and population health management.
- Streamlining access to care and advice for people who get ill but only use health services infrequently, providing them with greater choice about how they access care and ensuring care is always available in their community when they need it.



INTs aim to promote a culture of collaboration and pride, create the time and space within these teams to problem-solve together, and build relationships and trust between primary care and other system partners and communities. They help build a sense of shared ownership for preventing ill health and coordinating multi-disciplinary care as people's care needs escalate and de-escalate.

INTs will provide a new opportunity for health and care professionals, aligned to local voluntary and community sectors groups and communities themselves, to work together in new ways with new approaches to tackle the long-standing factors that have influenced the health inequalities that we currently see across NW London. INTs will be the vehicles for delivering new models of care and ensure that the right teams of people are brought together to reduce fragmentation for our population, improve outcomes, and make the most efficient use of resources.

With this in mind CPSC providers can build on integration within INTs to work together more effectively, leading to better-coordinated and integrated care for patients at the local borough level. This could include CSPC services leads attending multidisciplinary meetings and being part of case reviews. This is also an opportunity for CSPC services and other professional involved in the patient cases to agree a lead professional approach and ensure that appropriate training is embedded into the process to support this. This way the patient can be supported to have more continuity of care, as well as reducing the need to tell their story repetitively. It can also support to patient to get the right care at the right time through their lead professional.

Example INT: Multi-disciplinary teams for our frail population in Hammersmith and Fulham

The teams (MDT) consist of a general practitioner (GP), community staff, a weekly session with a geriatrician, and a dedicated social worker. The MDT members meet every week to discuss and create a joint care plan. They conduct home visits together, including the geriatrician when needed. Additionally, other specialised clinical staff like those in mental health, tissue viability nursing (TVN), continence, and dietetics may attend as necessary. The MDT utilises risk stratification to identify individuals with frailty and provides comprehensive, integrated support to help them stay at home and minimise hospital admissions. The MDT also assists in the successful discharge of frail elderly individuals to reduce the likelihood of re-admission.

12. Engaging on the new model of care and next steps

12.1 Tell us what you think?

We believe the proposed new model of care describes what good community-based specialist palliative care should look like in NW London for the next five years and beyond. The model of care responds to the needs of our population and authentically reflects the views of our communities, people with lived experiences of palliative and end-of-life care services and bereavement, our clinicians and our providers.

We appreciate this has taken longer than residents and stakeholders would have liked. However, we needed to make sure the model of care responds to the needs of our population and authentically reflects the views of our communities, people with lived experiences of palliative and end-of-life care services and bereavement, our clinicians and our providers.

This model of care is the culmination of time invested by all members of the NW London model of care working group to describe what high quality community-based specialist palliative care is required for our communities.

We are also pleased that the model of care is supported by the NW London community-based specialist palliative care steering group that included all hospice and NHS providers of community-based specialist palliative care services in NW London.

We now want to get feedback on our recommended model of care.

You can provide your feedback by completing our short online survey.

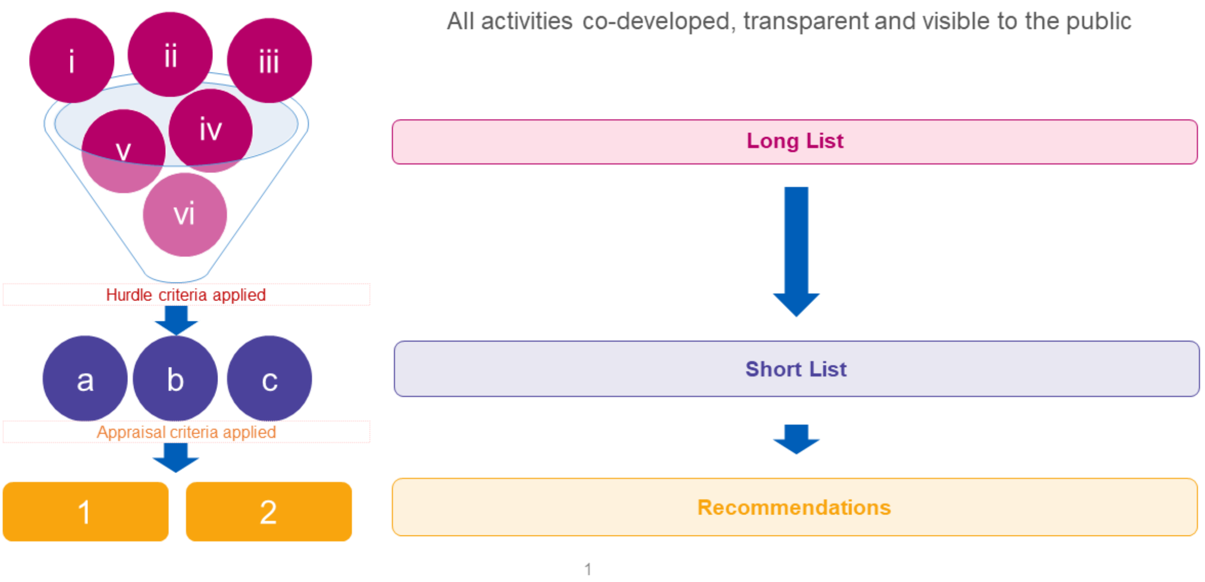
You can also provide feedback by attending one of our engagement meetings where we will be able to discuss where we have got to so far and answer your questions, please visit www.nwlondonics.nhs.uk/cspc to find out more.

In the meantime, if you have any comments or questions please email nhsnwl.endoflife@nhs.net

12.2 How we will use your feedback

We will analyse and consider all feedback received and make changes to the model of care as needed.

Diagram 1 - Developing the future model of care – options appraisal process



The next phase will require us to consider how we can introduce the model of care. At the outset of our work, we described a process where we would generate a long list of options through which we could deliver the change. We would then whittle these down using hurdle criteria that have already been developed and agreed by the model of care steering group.

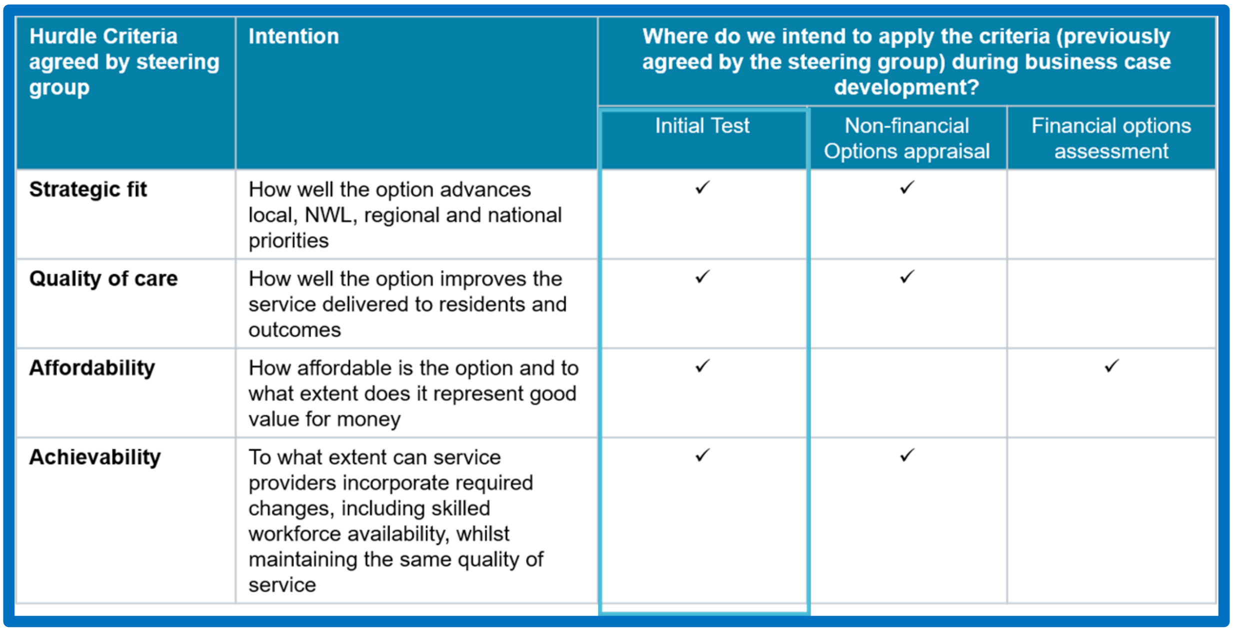
The shortlisted options would then require further development and appraisal before we identify recommendations.

Following the appraisal process, we will work with our Borough Based Partnerships, local residents and palliative and end-of-life care stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed.

If it is deemed that a substantial service change is needed, we will need to consider if a public consultation is necessary. If consultation is needed the options will then go into the development of a pre-consultation business case which will be presented to the NHS NW London Board for approval.

How we will use hurdle criteria to shortlist ideas

We will use hurdle criteria to filter the number of ideas generated through this engagement exercise in order to create a manageable short list of options that we can then analyse further. The hurdle criteria are detailed in the table below.



Hurdle Criteria agreed by steering group	Intention	Where do we intend to apply the criteria (previously agreed by the steering group) during business case development?		
		Initial Test	Non-financial Options appraisal	Financial options assessment
Strategic fit	How well the option advances local, NWL, regional and national priorities	✓	✓	
Quality of care	How well the option improves the service delivered to residents and outcomes	✓	✓	
Affordability	How affordable is the option and to what extent does it represent good value for money	✓		✓
Achievability	To what extent can service providers incorporate required changes, including skilled workforce availability, whilst maintaining the same quality of service	✓	✓	

Evaluation of short-listed options

Following the shortlisting, we will delve further into these four areas to examine the merits and shortfalls of the options.

An equality health impact assessment will then be carried out on the short-listed options.

We will then work with our Borough Based Partnerships, local residents and palliative and end-of-life care stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If it is deemed that substantial service change is needed, we will then need to consider if a public consultation is necessary.

12.3 Next steps

Engagement will continue and our current estimation is that we expect to be clearer on a set of recommendations emerging from the ongoing engagement and shortlisting process in Autumn 2023.

At that point, we will be able to communicate further details of our forward plan.

13. Concluding comments

We recognise the length of time the programme has taken to develop this model, but stand by the importance of doing this in partnership with local residents and we are grateful for your patience.

By taking time to listen to the views of our local residents and bringing together these voices with our clinicians and providers, we have designed something that is specific to our communities and our needs. It would not have been possible without the ongoing contributions of everyone involved.

By providing us with comments on the model of care described in this document, we believe you can help us move closer to agreeing what community-based specialist palliative care should look like in NW London.

We can then progress through the process outlined above to establish the best way of delivering the model of care.

Appendix A: NW London community-based specialist palliative care new model of care working group

What is the new model of care working group?

The new model of care working group was asked to develop and co-design a new model of care for community-based specialist palliative care, based on best practice and evidence, to help us develop high quality community-based specialist palliative care that is delivered equitably and sustainably across NW London.

The new model of care aims to make sure people have a choice, get the right care, at the right time, by the right team and in the right place, alongside their wishes and preference. Through it, all residents, no matter their circumstances, will be able to access the services they need.

Co-design is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of design. Whenever we are designing new services and patient pathways, it is important that anyone who would like to contribute has the opportunity to input into the process.

Who were the members of the NW London community-based specialist palliative care new model of care working group?

Membership of the NW London community-based specialist palliative care new model of care working group consisted of local residents and carers with lived experience of palliative and end-of-life care services, practitioners and other palliative and end-of-life care stakeholders.

It included:

- NW London NHS community specialist palliative care and NW London Hospice providers (Also see Appendix 1)
- Twelve patients and carer representatives
- Primary care representatives
- Acute hospital specialist palliative care representatives
- Acute hospital discharge representatives
- NW London care homes lead
- London Ambulance Service
- Community nursing representatives
- Continuing Health Care (CHC) representatives

We also invited additional topic or other programme related stakeholders when needed.

This helped ensure that the new model of care supports integrated care as it is developed with all appropriate interdependent programmes and considers the patient journey through the whole pathway.

What was the new model of care working group's remit?

The NW London community-based specialist palliative care new model of care working group was asked to:

- Develop a new model of care that will help us decide what type of services we need and what the common core offer that every patient in NW London should have access to.
- Develop a set of good practice and evidence-based core service standards, requirements and service definitions. These will demonstrate what we believe good community-based specialist palliative care looks like for all our residents.
- Develop a set of co-designed principles that will help us to successfully design and deliver the new patient-centred model of care across NW London.
- Support the development of a long list of options for delivery of the new model of care.

The model of care working group also looked at the future need of the NW London population over the next five plus years. In particular:

- The future requirements for in-patient bedded services and what they could look like.
- The principles by which we will decide the size and shape of future palliative in-patient services and the number of beds required
- The future requirements for other community-based services (hospice at home, community-based specialist palliative care teams, psychological and bereavement support, 24/7 specialist palliative care advice line, out-patients, day hospice services).
- The principles by which we will decide the size and shape of these community-based services for the future.
- They have also put forward recommendations as to what supporting services activity (for example, improving uptake of the London Urgent Care Plan (UCP) and having a workforce recruitment and retention plan) are needed to deliver good community-based specialist care services and the mechanisms for developing these programme enablers.

The model of care is being designed to support local flexibility and equity of access. This means that the local Borough Based Partnerships will have the ability to develop additional services beyond the NW London core service offer if they wish to, based on their local priorities and local population needs.

What happened in the model of care working group?

The model of care working group met 38 times over the course of twelve months or so and we thank them for their hard work and determination in helping us deliver excellent community-based specialist palliative care services for NW London residents. During the meetings they were provided with detailed background evidence and information and discussed what good community-based specialist care services should look like and what future capacity and demand for these services will be.

The background evidence and information they were provided with included:

- The eight broad reasons why we are doing this, national and regional good practice and evidence
- The wonderful, rich feedback we have received from our residents, healthcare professionals and various other stakeholders through our engagement
- The current and projected future demand for our services and the capacity and the structure of our workforce that will be needed to deliver it.

Many local residents have been kind enough to share their stories to illustrate both the good experiences and the challenges that people face when using community-based specialist palliative care services. We need to learn from their experiences and the feedback was used in the model of care working group meetings so it could directly influence the discussions taking place on a topic-by-topic basis.

The work of the review programme and the new model of working group to date

The minutes for the model of care working group's meetings can be found here.

A summary of the review programme's work is provided in the table below.

Task	Considered by the new model of care working group?	Further detail
Defining what the core elements of care and service delivery are	Yes	The national service specification for palliative and end-of-life care and the starting point for this work. The working group are further defining these based on our resident and population needs.
Defining how much of these key elements we need	Yes	This isn't covered in the national specification, but is critical if we are to make sure we are able to introduce a model of care across NW London. Note that 'How much' includes hours, staffing and capacity.
Defining how services should be delivered	Partially	For example, we may want to define elements such as access (including geographical availability) but not how services are integrated at a local borough level.
Defining where services are to be delivered	No	The new Model of care working group will put forward some recommendations that will be included in the long-list of service change options that will be developed further following more engagement with the public and other stakeholders. These options will go through an

		appraisal process and be subject to public consultation if deemed necessary
Who delivers elements	No	Future programme work once model of care and option have been agreed.
How much it costs	No	Not considered at this stage.

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Appendix B: The NW London community-based specialist palliative care steering group

The purpose of the NW London community-based specialist palliative care steering group is to provide executive oversight and governance as we seek to deliver quality improvements to community-based specialist palliative care.

- This includes providing strategic direction and decision-making, reviewing escalations and challenges from the working group(s) and determining where further escalation is needed.
- Ensuring there is robust engagement with the user/clinical reference group of patients and clinicians, and ensuring that cross-cutting functions of finance, communications, and data are incorporated consistently across the working group(s), including ensuring that data reporting requirements are provided to NHS NW London ICS, as required.

Who are the members of the steering group?

Key palliative and end-of-life care stakeholders (generalist and specialist) including two patient and carer representatives:

- NW London NHS community specialist palliative care and NW London Hospice providers (Also see Appendix 1)
- Two patient and carer representatives
- Clinical leads
- NW London Last Phase of Life programme and care homes GP clinical lead
- Acute hospital specialist palliative care clinical lead (consultant)
- Acute hospital specialist palliative care nurse lead
- Community services professional lead
- NW London ICS Local Care Programme Team (four members)
- NW London ICS Finance Lead
- NW London ICS Communications Lead

We also invited additional topic or other programme related stakeholders when needed.

Appendix C: Model of care development

Bibliography: Key documentation used in the development of the NW London community-based specialist palliative care new model of care

Local documentation

1. Engagement feedback engagement feedback
2. Strategic review of the palliative care that involved four CCGs (Brent, Hammersmith & Fulham, Westminster and Central London)

National documentation

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24. Independent report by Healthcare Safety Investigation Branch NI-000835: Variations in the delivery of palliative care services to adults (July 2023)

Appendix D: Continuum of care

What is a continuum of care in the context of specialist palliative care and hospice care services?

A care continuum is a description of how a patient would be moving up and down the levels of specialist support based on their changing needs and preferences.

In the context of specialist palliative care and hospice care services, a continuum of care refers to a seamless and coordinated progression of services that are tailored to meet the evolving needs and preferences of patients facing advanced illnesses. It recognizes that patients' care requirements change over time and ensures that appropriate levels of support are provided at each stage of their journey.

The continuum of care encompasses various levels of specialist support, with includes the following components:

- **Adult community-based specialist palliative care team:** This care is provided in the patient's home or community setting. It involves a team of healthcare professionals, including doctors, nurses, social workers, and counsellors, who specialize in palliative care. They focus on managing symptoms, providing emotional and psychosocial support, and helping patients and their families navigate the challenges of living with a serious illness.
- **Hospice at home service:** When a patient's needs become more complex, they may require additional support that can be provided through a hospice at home service. This involves a dedicated team of healthcare professionals who deliver comprehensive palliative care in the patient's home environment. They ensure symptom management, emotional support, and coordination of care, while respecting the patient's desire to be in familiar surroundings.
- **Hospice in-patient bed care:** In some cases, patients may require a higher level of care that cannot be adequately provided at home. Hospice in-patient care service offers a specialized facility where patients receive 24/7 medical support and symptom management. This level of care may be needed when a patient's symptoms become difficult to manage at home or when complex interventions, such as pain management, require a more controlled environment.
- **Hospice out-patient clinics, day care and well-being services:** Out-patient clinics provide specialized consultations, assessments, and treatments for patients who do not require in-patient care. Patients may visit these clinics for routine check-ups, medication adjustments, counselling sessions, or specialized interventions such as palliative chemotherapy or radiation therapy. Day care and well-being services aim to improve the overall well-being of patients and provide respite for caregivers. Patients attend day care centres or well-being programs where they can engage in therapeutic activities, receive social support, and access complementary therapies to enhance their quality of life.
- **Lymphoedema services:** Lymphoedema services are specialized programs that manage and treat swelling caused by lymphatic system dysfunction.

These services include assessment, compression therapy, exercises, and education to help patients manage and alleviate symptoms related to lymphoedema.
- Bereavement and psychological support services.
- 24/7 specialist palliative care advice line.
- Nursing home enhanced end-of-life care beds and enhanced care for care homes.

The movement of patients up and down the levels of specialist support within the continuum of care is based on their changing needs and preferences. As a patient's condition progresses or becomes more complex, they may require a higher level of care, such as transitioning from community-based specialist palliative care to a hospice at home service or a hospice in-patient care service. This may be due to worsening symptoms, increased care needs, or the need for more intensive medical interventions.

Conversely, as a patient's condition stabilises or improves, they may have the option to transition back to a lower level of care, such as moving from in-patient care to hospice at home or community-based specialist palliative care. This transition allows patients to receive the optimum care and support they need in a less intensive setting that aligns with their preference for being at home or in the community.

The movement within the continuum of care is driven by the goal of providing patient-centred care that matches the individual's needs and preferences at any given time. It ensures that the level of support provided is appropriate to address the physical, emotional, and psychosocial aspects of the patient's condition, while also considering the patient's desire for autonomy, comfort, and quality of life.

Overall, the continuum of care in specialist palliative care and hospice services offers a flexible and adaptive approach to meeting the changing needs and preferences of patients, providing them with the most appropriate level of support throughout their journey with advanced illness.

Patient story example

Sarah, a 65-year-old with advanced-stage cancer, received care at home from a palliative care team. As her symptoms worsened, she transitioned to a hospice at home service for round-the-clock support. When her pain became harder to manage, she moved to a hospice in-patient facility. After her pain improved, she returned to the hospice at home service. As her condition progressed further, she went back to the hospice in-patient facility for specialised care. The care team adjusted her support based on her changing needs to ensure comfort and well-being throughout her journey.

Appendix E: Summary of service improvements by NW London borough

Brent

Summary of service improvements for Brent 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 Brent 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. Brent residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Community specialist in-patient beds

- Brent 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 for residents in all boroughs of NW London. They are currently only available in Hillingdon.
- Brent residents will continue to have access to specialist hospice in-patient bed care.

24/7 specialist palliative care telephone advice

- Brent residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospice.
- This existing service will be expanded to support Brent 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

- Brent residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support.
- Brent 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 Brent 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 Brent residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Ealing

Summary of service improvements for Ealing 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 Ealing 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. Ealing residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Community in-patient bed care

- Ealing 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.
- Ealing residents will continue to have access to specialist hospice in-patient bed care.

24/7 specialist palliative care telephone advice

- Ealing residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospice.
- This existing service will be expanded to support Ealing 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

- Ealing residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of a common core offer lymphoedema support and expanded out-patient clinics to include medical and nurse led clinics
- Ealing 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 Ealing 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 Ealing residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Hammersmith and Fulham

Summary of service improvements for Hammersmith & Fulham 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 Hammersmith & Fulham 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 for the team will increase to 8am - 8pm from current 9am to 5pm. Hammersmith & Fulham residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Hospice at home

- Hammersmith & Fulham residents will have access for the first time a Hospice at Home service. This service currently does not exist.
- This service supports up to 24-hour care at home (including overnight sitting) if needed in close collaboration with usual community care teams.

Community specialist in-patient bed care

- Hammersmith & Fulham residents will have access to an increased number of beds in the community, which includes 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.
- Hammersmith & Fulham residents will continue to have access to specialist hospice in-patient bed care.

24/7 specialist palliative care telephone advice

- Hammersmith & Fulham residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospices/ specialist palliative care providers.
- This existing service will be expanded to support Hammersmith & Fulham 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

- Hammersmith & Fulham residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support.
- Hammersmith & Fulham 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 Hammersmith & Fulham 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 Hammersmith & Fulham residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Harrow

Summary of service improvements for Harrow 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 Harrow 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. The service will also be expanded to operate 7-days a week as opposed to the current 5 days a week (Monday to Friday). Harrow residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Community in-patient bed care

- Harrow 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.
- Harrow residents will continue to have access to specialist hospice in-patient unit bed care.

24/7 specialist palliative care telephone advice

- Harrow residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospice.
- This existing service will be expanded to support Harrow 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

- Harrow residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support, as well as expanded to support non-cancer lymphoedema diagnoses which is currently a gap in provision for Harrow.
- Harrow 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 Harrow 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 Harrow residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Hillingdon

Summary of service improvements for Hillingdon 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 Hillingdon 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. Hillingdon residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Community in-patient bed care

- Hillingdon residents currently have access to 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. This service will be improved through a common core offer that will be available to all boroughs of NW London.
- Hillingdon residents will continue to have access to specialist hospice in-patient unit bed care.

24/7 specialist palliative care telephone advice

- Hillingdon 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 Hillingdon 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

- Hillingdon residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support.
- Hillingdon 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 Hillingdon 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 Hillingdon residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Hounslow

Summary of service improvements for Hounslow 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 Hounslow 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. Hounslow residents will therefore have access to a 7-day service that operates 12 hours a day to support their care needs.

Community in-patient bed care

- Hounslow 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.
- Hounslow residents will continue to have access to specialist hospice in-patient unit bed care.

24/7 specialist palliative care telephone advice

- Hounslow residents who are known to community-based specialist palliative care services already have access to this 24/7 advice via their local hospice.
- This existing service will be expanded to support Hounslow 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

- Hounslow residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of lymphoedema support and expanded out-patient clinics to include medical and nurse led clinics
- Hounslow 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 Hounslow 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 Hounslow residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Kensington & Chelsea

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 Westminster 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.
- 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.

Westminster

Summary of service improvements for Westminster 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 Westminster 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. Westminster 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 specialist in-patient bed care

- Westminster 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 across all boroughs of NW London. They are currently only available in Hillingdon.
- Westminster residents will continue to have access to specialist hospice in-patient unit bed care.

24/7 specialist palliative care telephone advice

- Westminster 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 Westminster 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

- Westminster residents will continue to have access to out-patient clinics, including lymphoedema services that will be improved with a common core offer of support.
- Westminster 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 Westminster 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 Westminster residents, while creating a supportive and inclusive environment throughout all aspects of care and services.

Appendix F: Glossary

Term	Definition
Advance care planning	Advance care planning (ACP) is the term used to describe the conversation between people, their families and carers and those looking after them about their future health and care wishes and priorities. It is a way for a person to think ahead, to describe what's important to them and have this recorded to ensure other people know their wishes to help that person to live well right to the end of their life. Advance Care planning is a key means of improving care for people nearing the end-of-life and of enabling better planning and provision of care, to help them live well and die well in the place and the manner of their choosing.
Bed days	Bed days are the number of days a patient spends in a hospital, hospice, or healthcare facility as an admitted patient staying overnight. For example, if someone is admitted and stays for three days, that's counted as three in-patient bed days. This is used to see how long patients stay in beds for medical care. The individuals and organisations who commission or oversee these services use bed days as a way to measure and manage healthcare resources. It helps them understand how efficiently hospices and hospitals are working.
Borough based partnership	Borough based partnerships are collaborative arrangements between organisations responsible for arranging and delivering health and care services and others with a role in improving health and wellbeing. In NW London these are the eight local borough based partnerships who deliver the strategy. These partnerships include can include local authorities, primary care, community care, mental health, acute trusts and the voluntary sector. Each partnership is collaborating at borough level to tackle local challenges, improve the health and wellbeing of the local population and reduce the health inequalities that exist within their borough.
Care pathways	Care pathways map out the care journey an individual can expect. They are multi-professional, crossing organisational boundaries, and can act as a prompt for consistent approaches to patient care.

Clinical Nurse Specialist (CNS)	A Clinical Nurse Specialist (CNS) is a nurse with advanced knowledge and training in a specific area of healthcare. They are usually an NHS Band 7. They work closely with patients, providing specialised care and managing complex cases. They are experts in their field and may also be involved in research, teaching, and shaping healthcare policies related to their specialty. A CNS working in community specialist palliative care is a highly skilled and experienced nurse who specialises in providing expert care and support to individuals with serious life limiting illnesses. They work outside of hospitals, in the community, to help patients and their families manage pain, symptoms, and emotional challenges associated with life-limiting or terminal illnesses. These nurses are trained to understand and address the unique needs of patients who require palliative care, which focuses on enhancing their quality of life, providing comfort, and meeting their physical, emotional, and spiritual needs during this sensitive time. The CNS collaborates with a team of healthcare professionals to ensure that patients receive the best possible care and support, and they may also provide education and guidance to both patients and their families to help them cope with the challenges they may face.
Co-design	Co-design is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of service design.
Common core service / offer	A common core service or offer (in this context) describes a consistent standard to be provided across all services provided to the public in NW London. The terms of the common core service or offer are designed to make sure all the public in each of the NW London boroughs have access to a consistent level of high quality care, reducing inequality and unwanted variation.
Community-based specialist palliative care (CSPC)	Community-based specialist palliative care refers to providing specialised care for individuals with life-limiting illnesses and those close to them outside of a hospital, typically in their own homes, care homes, or hospices. These services aim to manage symptoms, enhance quality of life, and provide support during the end-of-life process. The goal is to collaborate with patients and their loved ones, tailoring care to meet their specific needs and wishes, and ultimately improving the overall quality of their life and death.

Complementary therapies	When a non-mainstream medical practice is used together with conventional medicine, it's considered "complementary". A number of complementary therapies and may be used with the intention of treating or curing a health condition with examples including homeopathy and acupuncture.
Continuing healthcare (CHC)	NHS continuing healthcare (CHC) is social care funded by the NHS and can be provided in a variety of settings outside hospital, including the patient's own home or a care home. It is sometimes called fully-funded care. A person's eligibility for NHS continuing healthcare is based on their assessed needs, and not on any particular diagnosis or condition.
Continuum of care	See appendix D.
Cultural competency	Cultural competence refers to an organization's or individual’s overall respect for and understanding of different cultures, as defined by nationalities, religions, languages, customs, behaviours and ethnicities and their ability to effectively interact, work and develop meaningful relationships with people or groups from different cultural backgrounds.
Discharge hubs	A discharge hubs role is to assess a person's ability to manage safely with daily tasks, supporting their discharge or admission to hospital. This typically involves working together with community and hospital based services.
Domiciliary home care staff	Domiciliary home care staff, also known as home carers or private carers, help people live independently in their own homes through daily visits or live-in care. Their role is focused on helping people with personal care, medication, household tasks and other activities which assist them in maintaining their quality of life.
Enablers	Enablers typically refer to essential components or “building blocks” that facilitate or support the successful implementation of a project or process They serve as fundamental pieces, that have impact across different aspects of the project or process and are supportive in the functioning of the system and delivery of good care

	They address ‘ways of working’ rather than new service elements and in this document we refer to five (see chapter 11) that we will need to develop and put in place to support the successful delivery of our new model of care.
End-of-life care	End-of-life care is a specific type of care for individuals nearing the final stages of their life. It aims to ensure comfort, dignity, and support, managing symptoms and providing emotional and practical assistance.
Equality and Health Inequalities Assessment (EHIA)	An Equality and Health Inequalities Assessments (EHIA) assess the (potential) impact of a decision on the “protected characteristics” as outlined in the Equality Act 2010.
Evaluation criteria	Evaluation criteria are a benchmark, standard, or factor against which conformance, performance, and suitability of a technical capability, activity, product, or plan is measured.
Health Care Assistants (HCAs)	Healthcare assistants or HCAs are an integral part of the team that supports medical staff and patients in many different care settings, including hospitals, GP surgeries and in the community. They typically work under the supervision of qualified nurses and carry out a wide range of tasks with the sole purpose of caring for, supporting and providing information to patients and their families. Some of the typical responsibilities of a HCA might include but are not limited to: looking after the physical comfort of patients; taking and recording basic observations such as blood pressure and temperature; helping patients to eat and to move about if they have mobility problems; catheter care (as well as inserting/removing); wound care; helping patients to mobilise and recover from surgery; and listening and talking to patients.
Home and usual place of residence:	What we mean when we say home or usual place of residence is a place in the community where a patient lives most of the time and feels comfortable. It's where a patient has their own space and belongings and normally live most of the time/ spend the majority of their days and nights. It's the place you call home. It could be an apartment, house, hostel or shelter, dedicated care setting (care home (nursing, residential, learning disability care home), sheltered housing and supported living accommodation and mental health facility) where you have a consistent living arrangement at this place. .

Hurdle criteria	A set of criteria used to filter the viability of options in a scenario or project. In this case of this project, the hurdle criteria will be used to filter the number of ideas generated through the engagement exercise in order to create a manageable short list of options that we can then analyse further. This will be undertaken by the NW London community-based specialist palliative care Steering Group, members of which include providers of care and patient representatives.
Integrated Care Boards (ICBs)	Integrated care boards (ICBs) replaced clinical commissioning groups (CCGs) in the NHS in England from 1 July 2022. An integrated care board (or ICB) is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area.
Integrated care systems (ICSs)	Integrated care systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. The NW London ICS consists of all NHS organisations and local authorities in NW London.
In-patient bed care	In-patient bed care refers to individuals needing and receiving care within in a dedicated healthcare environment (for example in a hospice, hospital or nursing home), which has round the clock medical support and monitoring from healthcare professionals.
In-reach	In-reach health services are medical services that are delivered to patients who are already admitted or residing in a particular healthcare setting, like a hospital, nursing home, or hospice. Instead of patients going out to seek medical care, the care comes to them within the confines of the facility where they are receiving care or residing. This approach aims to enhance patient access to necessary medical attention, convenience, and continuity of care while minimizing the need for external transfers or travel.
Generalist palliative and end-of-life care	Generalist palliative and end-of-life care is the fundamental level of palliative and end-of-life care support provided by

	healthcare professionals such as a general practitioner (GP), community nurses (including district nurses), care home staff, therapists, domiciliary home care staff (for example care agency staff either arranged by the council, through continuing health care or privately) and hospital ward staff who have a general understanding of and training in palliative care. They provide support to patients with serious illnesses or nearing the end-of-life in their usual place of residence (which may be their home, a care or nursing home or a sheltered housing facility) or a medical facility such as a hospital or hospice. The majority of people with life-limiting and advance illness will only need this level of support through their journey of palliative and end-of-life care.
Model of care	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.
Multidisciplinary teams (MDT)	A Multidisciplinary Team (MDT) is a group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients.
Palliative care	Palliative care is a treatment, care and support approach that focuses on improving quality of life by managing symptoms, relieving pain, and addressing the side effects of a patients’ condition. It also provides support for emotional and practical needs, along with those of family, friends and care givers.
Patient outcomes	Patient outcomes are the results from care and treatments patients have received whilst in hospital, other clinical or care settings.
Preceptorship	Preceptorship is a period of structured transition to guide and support newly qualified practitioners, helping them integrate into their new team and place of work.
Personalised care planning	Personalised care and support planning is a series of facilitated conversations in which a patient, their family or those close to them can actively participate in exploring the management of the patients’ health and well-being within the context of their whole life and family situation.
Single and double handed care	"Single-handed care" refers to providing care or assistance to someone using just one caregiver or healthcare worker.

	"Double-handed care" refers to providing care or assistance to someone using two caregivers or healthcare workers working together.
Specialist palliative and end-of-life care	Specialist palliative and end-of-life care is an advanced and specialist level of palliative and end-of-life care provided by expert health care professionals who have received specialised training in this field. Care is provided by a specialist palliative care multi-disciplinary team (doctor, nurse, therapist) who work with your regular care teams in the community to provide additional support and guidance for complex symptoms and challenges. This type of care is required by individuals with advanced and life-limiting illness that have complex needs (can be medical and social). This care is usually provided in special palliative care units, hospices, or at home/ usual place of residence via the specialist multi-disciplinary team across services. This type of specialist care is not required by everybody with palliative care needs and at the end-of-life.
Those important to the patient	The phrase ‘those important to the patient’ can refer to family, carers or friends that a patient wish to involve in discussions or decisions about the care they receive.
Triage	Most simply, the general purpose of *triage* is to sort patients by level of acuity to inform care decisions.
Unknown patients	By ‘unknown’ patients, we mean patients who have not previously received care from community specialist palliative care services (and are therefore not registered with, or are unknown, to the services).
Universal Care Plan (UCP	The Universal Care Plan (UCP) is an NHS service that enables people living in London to have their care and support needs and preferences digitally shared with healthcare professionals across the capital. It is the recommended platform for urgent and end-of-life care plans in NW London and London.
Virtual wards	Virtual wards allow patients to get hospital-level care at home safely and in familiar surroundings. Just as in hospital, people on a virtual ward are cared for by a multidisciplinary team who can provide a range of tests and treatments. This could include blood tests, prescribing medication or administering fluids through an intravenous drip.

	Patients are reviewed daily by the clinical team and the ‘ward round’ may involve a home visit or take place through video technology. Many virtual wards use technology like apps, wearables and other medical devices enabling clinical staff to easily check in and monitor the person’s recovery.

Appendix G current hospice out-patient, hospice day care and well-being services provision

Provider	Borough served for these services	Services provided (named as per provider website)
St Luke's Hospice	Harrow, Brent	**Out-patient clinic services:** These appointment based (one-to-one) consultant in specialist palliative medicine and specialist nurse led clinics (in person and virtual) provide access to specialist care with an emphasis on empowering patients to manage their own health and wellbeing through: • Ongoing monitoring and management of symptoms and conditions • Specialist advice on side-effects from treatment • Personalised care planning • Ongoing support, including coping strategies and psychological support • Signposting to other appropriate services **Well-being services:** These include: • Physiotherapy – a physiotherapist assesses the patient and provides an exercise programme to ease symptoms and maintain mobility and fitness. It helps prevent falls, strengthens muscle weakness and eases joint pain. Exercise groups are also offered. • Complementary therapy - Complementary Therapists work alongside medical and nursing staff to improve the wellbeing of patients and carers. The following therapies are offered: aromatherapy, massage, reflexology, reiki, relaxation, art & crafts, moments in life (memory work), gardening for hope. • Social activities and arts and crafts sessions. • Emotional and practical support – a specialist team including palliative care social workers, family support workers and trained volunteers provide additional emotional and practical support to help patients and those important to them. • Welfare benefits, advocacy and practical support - providing practical help, information and advice regarding welfare benefits, care packages, housing, transport and mobility (for example, disabled parking badges). • Supporting children – the team can work with patients to assess their children's needs and guide patient and family members in supporting children in the family. • Spiritual Care. • Advance care planning support.

		• Support for carers – a team of specialist workers and volunteers can meet with patients at the hospice, or in their own home (North Brent and Harrow), on their own or with anyone they choose to be there. They can provide emotional and practical support, explore ways to help carers cope, help build confidence and identify and develop personal, professional and community support networks. **Bereavement support service for family, carers and friends**: • The Bereavement Support Team provides bereavement support for anyone including family, carers and those important to them who has experienced the death of a loved one who was under the care of the Hospice. They offer one-to-one, group and virtual support as needed.
St John’s Hospice	Westminster, Hammersmith & Fulham (lymphoedema services only)	**Day care unit day services:** • The day care unit encompasses the hospice belief that hospice care is long-term and holistic – the focus is not only on physical care but on supporting the patient and those close to patient, to maintain quality of life, mental health and wellbeing. • At the day care unit at the hospice site in St John’s Wood, patients can access specialist nursing and medical care, benefit from treatments and therapies, meet with social workers and take part in workshops and activities. It is also an opportunity to meet other people who are living with life-limiting illness, have lunch and share experiences. • Care provided at the unit is tailored to each patient's individual needs and aims to ensure patients are supported physically, mentally, emotionally, practically and spiritually in as much as possible. • To do this, the services work as a multidisciplinary team (MDT) including doctors and nurses, therapists, social workers, bereavement counsellors, ambulance drivers and volunteers. The MDT will also work closely with other professionals involved in patient care such as GP, district nurse and hospital doctor. **Services offered:** • Out-patient clinic appointments (one-to-one): specialist nursing and medical care to support the monitoring and management of any pain and symptoms patients may have. They also provide interventions, such as drug therapy, infusions and blood transfusions.

		• **Physio and occupational therapies** to help maintain function and mobility, enabling patients to live as independently and fully as possible. • **Complementary therapies** including massage, reflexology, reiki and acupuncture. These can help to promote wellbeing, a sense of relaxation and relieve some of a patients' symptoms. These therapies are also available to family members and carers. • **Emotional and practical support and advice from social workers,** helping with any anxieties or concerns that patient or those close to them may have. This includes providing support with benefits, housing or financial matters. • Regular creative and physical activities including art, music and movement classes. • Transport to the day care unit via St John's ambulance service for patients with reduced mobility or access issues. **Lymphoedema care services:** • A team of lymphoedema practitioners provide specialist treatment to help patients regain their quality of life, mobility and ease discomfort when living with the condition lymphoedema. They can also provide patients with the information to better understand the condition and the things they can do to manage it. • What the service offers (for patients in Hammersmith & Fulham, Kensington & Chelsea and Westminster): • Advice and support with skincare to help improve skin health and to reduce risk of infection (Cellulitis). • Advice on the use of compression garments such as sleeves or stockings to reduce/control swelling, prevent a deterioration of the patients' condition, improve mobility and ease discomfort. • Information on exercises that a patient can do at home to promote lymphatic drainage in the affected area(s) and to improve mobility. • Manual Lymphatic Drainage (MLD) sessions for patients suffering from head and neck, breast or genital lymphoedema. • Signposts to additional support and resources available to help manage the condition, such as community care support. **Bereavement support:** • Services for adults and children to support them through bereavement after the loss of a loved one.

		• Group or individual adult bereavement support and counselling for family members, carers and friends. • This can include support for preparing for the loss of a loved one and finding ways of remembering them in the way that a person wishes. • The team includes a counsellor who specialises in adult bereavement as well as social workers who are also able to provide help with informal pre-bereavement support and anticipatory grief. • Support for children - recognising that children and young people can find it particularly difficult to understand and cope with bereavement, support specifically tailored to children is offered. As well as one-to-one support, the service creates opportunities for them to meet up with peers who have also experienced loss. Guidance and support can also be provided to parents and carers, as well as support and training to teachers on how to best help children through this experience. This support is provided by a dedicated child bereavement specialist. • Specific support available: • Group or individual adult bereavement counselling sessions for family members, carers and friends, providing a safe space to talk about the experience of grief and bereavement with a trained counsellor. • Group outings where bereaved adults can meet up with other bereaved adults who have also experienced loss through palliative care. • One-to-one bereavement support and counselling for children and young people (up to 18 years old) at their homes, at school or in their dedicated children’s room. • Activity days and group outings where children can meet up with their peers who have also experienced the loss of a parent. • Support and guidance for parents and carers of bereaved children. • Specialist training and advice to schools and other organisations working with children facing bereavement.
Royal Trinity Hospice	Westminster, Kensington & Chelsea, Hammersmith & Fulham	**Living well and out-patient services**: • Brand new support service launched in May 2023 providing patients and those close to them with a range of free classes, and group activities aimed at supporting and enhancing day-to-day living. • This programme of support, care and activities is specifically for patients under Royal Trinity hospice’s care who are living at home or other locations within the community such as care homes, nursing homes

		and temporary accommodation. It is a programme for out-patients, but the activities take place on site at Royal Trinity Hospice. • It includes the following clinics: o Breathlessness group. o Fatigue management group. o Physiotherapy - the physiotherapy team can support patients to control their symptoms including; breathlessness management, pain, mobility issues, transfers, and help to increase exercise tolerance and muscle strengthening. The sessions are one-to-one and last up to an hour. The number of sessions will be decided with the patient by the therapist, based around their goals and needs. o Occupational therapy – one-to-one sessions with an occupational therapist to help provide information and techniques to improve safety, independence, and quality of day-to-day life. Discussing a range of solutions available can also help manage fatigue and anxiety. These sessions may be in addition to, or instead of other group activities led by the occupational therapy team. o Dietectic service – providing expert nutritional advice. o Relaxation group. o Move with Trinity exercise group - run by expert physiotherapists, the group supports patients to maintain and improve their activity and exercise tolerance, muscle strength, co-ordination, balance, and posture as well as managing symptoms such as breathlessness, pain, and fatigue. At the group patients take part in a circuit of activities with graded exercises tailored for each patient. o Mindful movement group. o Complementary therapy - including massage, aromatherapy, reiki, reflexology and acupuncture. o Practical support for friends, families and carers - welfare benefits check clinic and carer clinic o Online well-being activities o See patient leaflet on provider website for more information about these clinics **Care for families, carers and children**: • **Bereavement support** service offering formal and informal group and individual support for family

members, friends, children, and carers through the emotional impact of grief following the death of a patient.

Therapies team:

- The therapies team offers everything from expertise and advice, to equipment to palliative rehabilitation. That might mean providing equipment to help people maintain their independence at home and maintain their access to everyday essentials like their bath or kitchen, or helping to rebuild strength, maintain their balance or manage their breathing.

Psychological, spiritual, social, and practical needs – one-to-one support for bereaved people:

- Trained counsellors and bereavement support volunteers provide support with a series of one-to-one counselling and bereavement support. This support can take different forms depending on what the patient needs and what the professionals think is best, in consultation with the patient. The idea is that whatever support the patient needs is tailored to their own experience and needs.
- The one-to-one support they offer for people who have had a friend or family member die under Trinity's care includes bereavement support, spiritual care support, social worker support, counselling, emotional support, and mindfulness. The number of sessions will depend on the professional seen and the approach that they take.

Dementia care services:

- There are a number of dementia services available for people who live in their own home or in a care home within Trinity's catchment area.
- The service aims to ensure people living with dementia, and their families and friends, have the same access to specialist palliative and end-of-life care as those living with other progressive, life-limiting illnesses such as cancer.
- The specialist service aims to provide dedicated support and advice to help people with dementia make decisions about their future care.
- The services their community dementia team provide includes:
    - Advance care planning to help people make decisions and record their wishes for care in the future.
    - Support for families and friends who care for someone with dementia.

		• Managing symptoms such as pain, distress and anxiety. • Advice and training for professionals who care for people in the later stages of dementia. • Liaising with other services and signposting.
Marie Curie Hospice Hampstead	Brent	**Out-patient services and day therapies:** • Out-patient services and day therapies support patients to live in the best way they can with a terminal illness. On a patient's first visit, they will see a doctor or clinical nurse specialist with whom the patient discusses their medical history, worries and concerns. • The team will help patients by working out the best care package for them and will review this regularly together to make sure it continues to suit patient needs. • Day therapies cover things like: ○ helping control symptoms ○ end-of-life care ○ Rehabilitation ○ emotional and spiritual support ○ family support ○ advance care planning. **Out-patient clinics:** • **Doctor-led clinics -** Doctor-led clinics are run by the hospice specialist palliative care doctors, in partnership with nurses. They help patients with: ○ expert advice on, and monitoring of, symptoms, which may include pain, breathlessness and fatigue ○ advance care planning ○ assessment for physiotherapy ○ referrals to other hospice day therapies, including physiotherapy ○ support with end-of-life care needs ○ liaison with other professionals involved in patient care, such as the medical or oncology team, community clinical nurses or GPs ○ reviewing care packages to make sure they continue to be right for the patient ○ support if patient is in remission, but has ongoing needs caused by their illness or treatment. • **Nurse-led clinics -** Run by clinical nurse specialists, these clinics help patients with: ○ an initial assessment of needs ○ controlling and managing symptoms

		o advice on medication changes o psychological support o advance care planning o end-of-life care o referrals to other day therapy services o support for end-of-life care needs o support if patient is in remission, but has ongoing needs caused by their illness or treatment o liaising with other professionals involved in a patients’ care, such as the medical or oncology team, community clinical nurses or GPs o reviewing care packages to make they continue to be right for the patient. • **Carers' clinic -** specialist nurses see carers of patients who are known to Marie Curie. The clinic supports carers by addressing their questions and concerns and signposting to other services. The clinic is nurse and social worker-led and offers face-to-face consultations. Referrals can be made for complementary therapies and further emotional support. • **Physiotherapy -** Physiotherapy helps patients maximise their physical fitness, strength and stamina to help them live as independently as possible. The physiotherapists will give advice and practical help to patients and their carers, beginning with a discussion about the patients’ abilities, limitations and what they want to achieve. Some of the things physiotherapy can help with are: o exercise programmes for muscle strength, joint flexibility, balance and coordination in the gym o breathlessness and fatigue management, including breathing exercises, exercise pacing and advice o pain relief - exercise advice and TENS machines for managing pain o techniques for changing position, for example moving in bed, moving to a chair, walking o walking aids such as sticks and frames to make it easier for you to move around independently. • **Occupational therapy -** occupational therapists help patients with: o practical information and advice about how to live as independently as possible at home o referrals and liaising with their local community occupational therapist for a home assessment and provision of equipment and aids such as

		rails, toileting equipment or bathroom equipment. • **Social work and the family support team** - help the patient, their family and carers. They give benefits advice, emotional support, help to liaise with community services and support with any other issues. • **Counselling for adults -** trained counsellors offer specialised emotional support and counselling for people living with serious illnesses. They're trained to be able to discuss topics such as depression and anxiety, coping with physical symptoms such as chronic pain, issues around end-of-life care and how to talk to family. • **Counselling for children, young people and families -** the children and young person's counsellor provides emotional support for children and advice for families when a relative or loved one is seriously ill. They also provide bereavement support to children and young people. • **Bereavement support –** this service supports loved ones with the death of someone close, both before and after they die. Bereavement support at the hospice is available as both one-to-one sessions and group sessions, depending on patient needs. • **Art therapy -** when thoughts and feelings are difficult to put into words, many people find art therapy helpful. • **Spiritual and religious care -** open to all faiths, traditions and beliefs, the hospice chaplain offers compassionate listening and the chance for you to share thoughts and concerns in a non-judgemental environment. • **Complementary therapies -** a range of complementary therapies are offered at the hospice and can be used alongside conventional medicines. These include acupuncture, aromatherapy, craniosacral therapy, massage, reflexology, relaxation, reiki and sound baths. • **Family support team for emotional practical and spiritual support** - this team provides expert emotional, practical and spiritual support services to patients, their families and those close to them. It is made up of social workers and chaplains. The team offers one-to-one support sessions for adults, one-to-one bereavement support sessions for children and therapeutic support sessions, such as help making memory jars, memory boxes and letter-writing. A hospice chaplain and volunteer chaplains can offer support if patients have concerns and thoughts about

		the bigger, deeper questions of life. The chaplains can contact religious leaders from many different faith communities to support the patient in the way that best suits them.

Harlington Hospice	Hillingdon	**Well-being services:**
		- These services support the wellbeing of people living with serious or terminal illness and those close to them.
		- There are a range of free sessions and activities available at Lansdowne House, the Reg Hopkins Centre, Michael Sobell House, in patients' home and online.
		- They offer a range of services including:
		  - Lymphoedema services
		  - Tripudio Movement Systems
		  - Legs eleven group
		  - Creative arts for well-being
		  - Rehabilitation team – therapy input from allied health professionals
		  - Relaxation class
		  - Exercise class
		  - Coping with fatigue group
		  - Dementia carers groups
		  - Complementary therapies, including massage and reiki
		  - Workshops for carers
		  - Spiritual support
		  - Digital affairs support
		
		Psychological & Emotional Support services:
		- Harlington's expertise in art psychotherapy, family therapy, counselling, palliative psychotherapy and patient & family support means they can work with people to have difficult conversations that lead to meaningful outcomes.
		- They listen to what is happening in the patients' world and provide a safe space to explore any concerns they may have.
		- Often through this process, people find that feelings of anxiety and worry surrounding death begin to feel less overwhelming.
		- This includes support for children and young people facing the illness of someone important to them. And those who have been bereaved for any reason.
		
		Harlington's Psychological & Emotional Support Services include:
		- **Counselling -** counselling is a talking therapy which can help a person to talk about the difficulties they are facing in a safe, confidential and non-judgmental

		space. A counsellor will help the person to process and explore these difficulties, so that they can gain a better understanding of themselves and how they cope with the issues they face. A counsellor does not give advice or tell a person what to do, but they can help someone develop their own way of coping and decision making. • **Patient & Family Support and Palliative Psychotherapy** - for those being admitted to the in-patient unit (IPU), whether for symptom control, pain management or at the end-of-life, just coming through the doors of a hospice can feel overwhelming. The patient & family support team offer a calm understanding of the huge range and intensity of emotions that may be experienced. They also bring a broad experience of the common and complex issues a serious or terminal illness can bring **Other services:** • **Palliative psychotherapy -** Having a terminal diagnosis, dealing with ill health and facing the end of-life bring enormous and often overwhelming emotions. There is a loss of health, the loss of an imagined future and perhaps most painfully of all the reality of saying goodbye to family and loved ones. This is a lot for a person to deal with on their own. Palliative psychotherapy provides support to process these issues in a safe space with a therapist experienced in all aspects of end-of-life care. Some people ask 'what is talking about it going to achieve'? The process of talking about experiences can empower a person to express their understanding of what is going on for themselves, and make sense of often incomprehensible feelings or situations. It can be an opportunity to grieve, to reflect on memories and relationships, or just to feel a little calmer and able to cope. The process can be individual but it can also involve family and loved ones to come to a shared understanding of being at the end-of-life. • **Community palliative counselling** - If a patients serious or terminal illness prevents them from accessing counselling at Michael Sobell House or Lansdowne House, face to face counselling is offered for patients and couples in their own home. The community palliative counsellor can visit and provide a space in which to safely explore the complex or overwhelming emotions which may arise for those with a diagnosis. To access this service, a patient must have a serious or terminal diagnosis, be unable to access counselling services due to immobility or

		severity of illness and be referred by the NHS community palliative care team.
		- **Child & adolescent bereavement service (CABS) –** Working alongside children, young people and families to navigate illness and grief. The child & adolescent bereavement service (CABS) offers support for children and young people facing the illness of someone important to them, or after someone has died. The impact that death and illness can have on children and young people's studies, relationships and development into adulthood is well known. Each child or young person will express their grief and emotions differently. This may take the form of appearing to be coping fine or having changeable behaviours such as sadness, anger, night terrors, anxiety, guilt and physical pain, or difficulties concentrating or attending school. The CABS team are alongside them and their families to help them navigate these feelings, supporting each individual through what can be a painful and disorientating experience. Specifically, the team offer support to children and young people aged 4–17 years, and their families, who live in the London Borough of Hillingdon and have experienced bereavement or have someone close to them with a serious or terminal illness. This support can include:
		  - Individual art therapy sessions
		  - Group art therapy
		  - End-of-life support and conversations
		  - Family sessions
		  - Parent support groups
		  - Advice for families & professionals
		  - Memorial events & creative workshops
		  - Psychoeducation for parents and carers.
		- **Bereavement counselling -** Harlington's Bereavement Counselling service is run through Hillingdon Mind and provides counselling to help support people through the difficult time after experiencing bereavement.

Pembridge Palliative Care Services provided by Central London Community	Westminster Hammersmith & Fulham Kensington and Chelsea South Brent	**Day hospice** – providing specialist palliative care treatment, support and complementary therapies for patients who are able to visit the service site at St Charles Hospital from home. The multidisciplinary team consists of nurses, a healthcare assistant, massage therapists, an art teacher and a spiritual care advisor. Doctors and social workers are also available to help if needed. The following services are offered:

Healthcare NHS Trust		• Symptom control - including medical assessments by nurses and doctors working with the palliative care service, including review of symptoms and medications. Ongoing monitoring of symptom control and effectiveness of treatment by the nursing staff and doctors. Patient education regarding symptoms and medication. Non-pharmacological methods of aiding symptom control such as massage. Ambulatory bisphosphonate clinic (specific referral needed). • Nursing care. • Rehabilitation & respite - a range of complementary therapies (massage therapy) and support services are offered including arts & crafts, occupational therapy, spiritual support, emotional support, exercise and relaxation classes. • Psychological support - one-to-one time with nurses and a spiritual care advisor and social workers if needed. Pembridge also offers: • **Specialist palliative care social work team** - who support patients and their families across the various Pembridge Services. They work holistically, combining counselling and practical skills, to assist patients and their families to achieve what is most important to them. They can meet with patients at the Pembridge site or at their home and provide: ○ Counselling support to patient and those important to them (one to one or as a family unit). ○ Practical support and advice - information relating to: finances and benefits, advance care planning, wills, or help with care in the home. ○ Support for children and teenagers. ○ Bereavement support for adults, children, family and friends. • **Spiritual support** - all staff at Pembridge are trained in listening to and caring for spiritual needs. There is also a dedicated spiritual care advisor who offers appointments with patients and those important to them.
Meadow House Hospice provided by London North West	Hounslow Ealing	**Out-patient day service and well-being services:** • **Therapy services** - Depending on what patients and families are experiencing, different team members can be involved. The therapy service accepts referrals from clinical nurse specialists or other specialist colleagues, from primary care or anyone

University Healthcare NHS Trust		else involved in the patient's care. They do not offer a rehabilitation service, but work closely with the local rehabilitation service in Ealing (Enable), particularly when the patient has longer term needs. The physical changes brought on by serious illness can create problems with mobility, self-care, general strength, weight loss and loss of energy. The following can sometimes help patients and families to cope better with these challenges: home adaptations, extra equipment, walking aids and advice about diet and how to conserve energy. The Allied Health Professionals at Meadow House Hospice include: physiotherapists who can assess mobility, strength and safety; occupational therapists who can advise on practical matters such as dressing, bathing and how to cope with everyday tasks; dieticians who providing advice on diet and supplements. • **Lymphoedema service** - a nurse-led out-patient clinic service that takes place at the hospice site. It provides advice and therapy for lymphoedema. The treatment can include: o Manual lymph drainage – focussed massage to try to shift and reduce the fluid trapped in the tissues. o Bandaging and hosiery – special garments which put gentle pressure on the limbs to try to prevent re-accumulation of fluid in the tissues. • **Bereavement service** – offering one-to-one grief counselling via a carefully selected volunteer that has gone through extensive counselling training under professional guidance from bereavement service expert leads. • **Day service** – offering support including complimentary therapies (reflexology and massage) to patients who are able to come in from home to spend the day under the care of the day service team at the hospice. Day service is not suitable for patients who are significantly confused, who can only be moved by stretcher, or for those with acute medical problems The team include a doctor, nurses, volunteers, complementary therapists and chaplaincy. • **Family support service** - helping patients and families to cope with emotional, psychological, social and financial difficulties in the context of serious illness or as dying and death approach for their loved one. The service includes a benefits advisor, two social workers and a clinical psychologist. Patients and family members can request this support if they feel the need for counselling or non-medical advice or be referred by other hospice service teams.

		• **Meadow house palliative care psychological support service Team email: lnwh-tr.cancer-psychology@nhs.net (website in progress)**