

Community-based specialist palliative care for adults:

Co-designing a new, improved model of care

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

This is a summary of the full paper that sets out the proposed model of care.

To see the full model of care engagement document, visit www.nwlondonics.nhs.uk/cspc

Our vision and aims

NW 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.

In North West London (NW London) we have some excellent 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 day centres), 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.

In late 2021, we set out the reasons we needed to improve 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 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.

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

The eight key issues we need to respond to	Key examples of how the issue has been built into the approach or model of care
<p>1 Respond to future need</p>	<ul style="list-style-type: none"> 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.
<p>2 Address service variation</p>	<ul style="list-style-type: none"> 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.
<p>3 Respond to inequalities</p>	<ul style="list-style-type: none"> 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

		<p>part of the next phase of this work to understand impact of proposed options to deliver the new model of care.</p> <ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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.

Since then, we have worked with our communities of residents, clinicians and providers in NW London to agree what makes high-quality, safe, and fair community-based specialist palliative care, as well as the crucial elements that contribute to an excellent experience to patients, families, carers and those important to them.

We have been fortunate to receive feedback from 188 people who responded to surveys and we listened to views of many more through 10 public events and 14 sessions within specific communities, including faith communities. We received a tremendous amount of feedback and published the findings in an [Engagement outcome report](#) which you can find on our [review webpage](#). We used the valuable insights from members of the public to feed into development of a new model of care that is described in this document.

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.

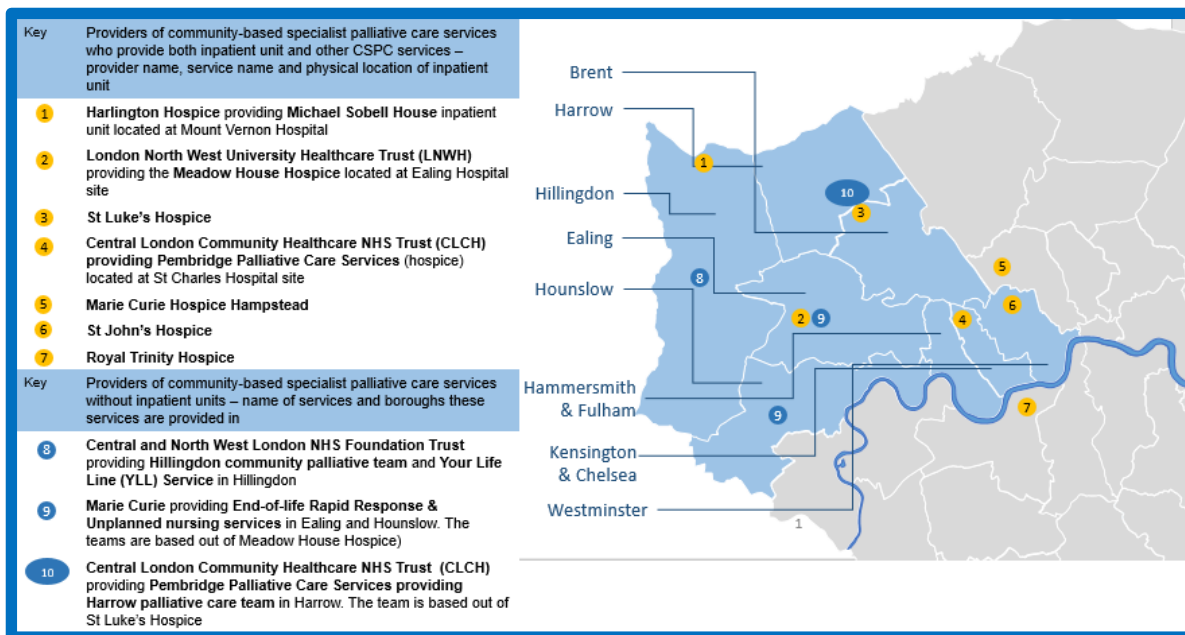
What is community-based specialist palliative care?

Community-based specialist palliative care services include care and support services that are not provided in an acute hospital or your local general practice surgery. Instead, they are provided in a community setting such as a patient's own home, a care home, a hospice, a community hospital or health centre. The focus of community-based specialist palliative care services is managing symptoms, improving quality of life, and supporting patients and those important to them when needed during their end-of-life journey.

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 [\(click here to view a larger view\)](#)



Developing a new model of care for community-based specialist palliative care for adults

In May 2022, the NW London community-based specialist palliative care model of care working group was established and included citizen representation (local residents and carers with lived experiences of palliative and end of life care needs and services), clinicians and current providers of community-based specialist palliative care.

The group met over thirty times to co-design and develop a new model of care that we believe will meet the needs of NW London residents for the next five years and beyond.

This document and its [fully detailed counterpart](#) represent the culmination of time and energy invested by a large diverse group of people and we are thankful to them in helping us get to this point.

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.

Recommendations

The model of care working group have collectively agreed and recommended a set of core services 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 the standard of care where these services do not exist or vary a lot.

While hospice inpatient beds remain a vital part of the offer, the model of care working group recommends strengthening other aspects of our services to enable more individuals to be supported at home and have their end-of-life wishes fulfilled.

The recommended model of care has three key service areas, each providing different services to meet patient needs. These 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.

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, 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 recommended new model of care, and achieve the improvements in care we are able to deliver:

- Workforce development
- Reducing inequalities
- Data, digital and technology

- Organisational development
- Leadership, governance and integration

Work will be undertaken to scope and define the various task and finish groups for each of the enablers between August and October 2023.

Next steps

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 and its fully detailed counterpart [\(insert link to full document\)](#).

This public engagement process will continue throughout the summer and early autumn 2023. However, engagement on the overall model of care will continue beyond this as we progress to business case development and implementation of any agreed changes.

During this engagement phase, we aim to engage widely and work with our public and stakeholders to:

- Provide an overview of the development process followed to date.
- Outline the contents of the proposed new model of care.
- Seek feedback and answer questions from the public on the new model of care.

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.

Visit www.nwlondonics.nhs.uk/cspc to find out how you can give your views on the new model of care.

Next steps after this engagement phase

From late autumn 2023 onwards we will:

- Publish feedback received and potentially a revised model of care which has considered that feedback.
- Explain the next steps in the process for having the model of care agreed and implemented for NW London.
- Develop a long-list of options for delivery of the new model of care with the steering group conducting the initial shortlisting.
- Then move to the next stages of making recommendations about options for any formal consultation, should this be deemed necessary.

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.