Report Title:

Update on the 'Compassionate care for all' public consultation and proposals for the north west London model of care for adult (18+) community specialist palliative care (CSPC) services

Committee Date:

01 May 2025

Report Deadline:

23 April 2025

Appendices:

Appendix 1 – Compassionate Care for All Consultation Document

Appendix 2 – Pre-consultation Business Case

Appendix 3 – Equality Health Impact Assessment

Appendix 4 – London Clinical Senate Report NWL Palliative Care

Appendix 5 – Compassionate Care for All Service Improvements by Borough

Appendix 6 – Frequently Asked Questions

Purpose

To provide an update to the North West London Joint Health Overview and Scrutiny Committee on the consultation, emerging themes and anticipated next steps for the implementation of a new, consistent model of community specialist palliative care (CSPC) across north west London.

Acknowledgment

We would like to thank all the members of the public who have given up their time throughout the review and provided their thoughts and feedback. Their energy, insights, ideas and challenges, along with the good and bad experiences of care their loved ones received, have directly informed the model of care that we wish to introduce.

Introduction

The consultation represented a pivotal moment for palliative and end-of-life care in north west London. The proposed model of care has been shaped by extensive engagement and co-design with residents, community organisations, clinicians and NHS and charitable providers since December 2021. This has included multiple phases of engagement, targeted outreach to underrepresented communities, the input of specialist working groups and a comprehensive Equalities Health Impact Assessment (EHIA).

The consultation has been an important opportunity to listen to residents and work together to shape the future of these important healthcare services. We are grateful for the engagement and thoughtful contributions from the community, which have been instrumental in refining the proposed model of care.

Feedback has been central to shaping the direction of the model. This includes, for example, the introduction of **enhanced end-of-life care beds across all boroughs**,

which are designed to bridge a gap in our current healthcare provision that many residents who contributed to the development of the proposed new model of care identified. These beds address the needs of patients who do not meet the criteria or need for a hospice inpatient bed, but can't stay at home, do not wish to stay at home or prefer not to be in a hospital for their care. This is especially true for those living alone without a local support system. They also offer the possibility of short-term respite care.

Partner support

- NHS North West London acknowledges and values the support from all stakeholders, including the NHS and four charitable hospices – Central London Community Healthcare NHS Trust, Central and North West London NHS Foundation Trust, Harlington Hospice, St Luke's Hospice, St John's Hospice, and Royal Trinity Hospice
- All have confirmed their support of the new model of care and have played an active role in the steering group that has guided the programme.
- Their expertise and contributions have been vital in co-designing a model that respects the diverse needs of patients, families, carers and friends.

In a time of significant financial pressure across the NHS and during ongoing organisational change, NHS North West London is taking a proactive, forward-looking approach. This model is about **levelling up services** and ensuring that every adult in north west London, regardless of where they live, can access consistent, culturally competent and high-quality specialist palliative care. It is designed to deliver **real, tangible improvements for patients, families, carers and friends**, providing better support outside of hospital, more timely advice, and a clearer, more coordinated care journey.

The proposed changes also recognise the need for financial sustainability. Whilst both options passed the core affordability test during the shortlisting financial assessment, **Option A**, NHS North West London's preferred implementation approach, delivers all the benefits of the new model **with a smaller additional financial ask and maintains support at the current or a higher level for charitable providers**. In contrast, **Option B**, which would reopen the Pembridge inpatient unit, would require significant new financial and staffing investment, delaying implementation and would lead to a reduction in funding of our charitable hospices, at a time when they face significant financial challenges.

Background and case for change

Access to community specialist palliative care in north west London has been inconsistent for many years, with significant variation in what services are available depending on where a person lives. This includes differences in access to:

- Hospice at Home
- community specialist palliative care team support

- out-of-hours support
- psychological and bereavement care.

As a result, many residents, especially those from under-served, global majority or marginalised communities—have been unable to access the support they need. This has contributed to increased hospital admissions, variation in place of death, and inequitable care at the end of life.

The "Compassionate Care for All" programme, led by NHS North West London, the integrated care board (ICB), has sought to address this inequity by designing a single, consistent model of care for all eight boroughs, co-produced with patients, carers, clinicians and providers.

Context and case for change

National context

Palliative and end-of-life care services support people who have a terminal diagnosis or are approaching the last year of life. These services play a crucial role in improving quality of life, reducing unnecessary hospital admissions, and providing care that respects people's choices.

Demand for these services is rising. As people live longer and with more complex conditions, the need for specialist palliative care is expected to increase significantly. National estimates suggest that by 2040, the number of people requiring palliative care in England and Wales could rise by between 25% and 47%.

In response to this, national policy has strengthened the role of integrated care boards (ICBs) in commissioning services that are personalised, high-quality, and meet the needs of local populations. In 2022, ICBs were given statutory responsibility for commissioning palliative and end-of-life care, with a requirement to carry out a gap analysis against the six national ambitions for palliative and end-of-life care.

Figure 1: Ambitions for Palliative and End-of-Life Care

Ambition 1	Ambition 2	Ambition 3	Ambition 4	Ambition 5	Ambition 6
Each person	Each person	Maximising	Care is	All staff are	Each
is seen as	gets fair	comfort and	coordinated	prepared to	community is
an individual	access to	wellbeing		care	prepared to
	care				help

Local context

In north west London, as of April 2024, approximately 35,600 people (1.52% of the population) are considered to be in the last phase of life. In 2023/24, 4,352 people died with a Universal Care Plan (UCP) in place. Of those who had recorded preferences, 67.9% died in their preferred place. While this is encouraging, it also highlights that a significant number of people do not have care preferences recorded, and work remains to be done to improve access and equity.

The current configuration of CSPC services varies across our eight boroughs, leading to differences in what services people can access depending on where they live. In some boroughs, inpatient hospice services are not available locally. In others, community-based support such as hospice at home is either not available or limited in hours. We also know that demand is not evenly distributed and this has implications for future planning. The map of provision is a complex arrangement of commissioners, including lead commissioner arrangements, and providers. These providers have mixed funding models:

- NHS-funded providers Central London Community Healthcare NHS Trust (CLCH), Central and North West London NHS Foundation Trust (CNWL) and London North West University Healthcare NHS Trust (LNWT).
- **combined NHS and charitable funded providers -** St Luke's Hospice Harrow, Harlington Hospice, Royal Trinity Hospice and St John's Hospice.

Why change is needed

Since 2021, we have been working with local residents, clinicians and providers to explore how services could be improved. This engagement identified eight key issues that make up the case for change. These include:

- variation in access to community specialist palliative care services
- limited access to 24/7 community specialist palliative care advice and support
- inconsistencies in access to psychological and bereavement services
- inequalities in outcomes, particularly for people from minority ethnic backgrounds
- gaps in the provision of hospice at home services
- limited access to specialist palliative care inpatient beds in some boroughs
- fragmentation in how services are delivered and coordinated
- challenges in recruiting and retaining a skilled palliative care workforce.

In addition to these long-standing issues, we also recognised that we had to resolve the future of the Pembridge Palliative Care Centre consultant-led inpatient unit beds, which were suspended in 2018 due to an inability to provide safe and consistent consultant in specialist palliative care.

This programme is about addressing these issues through a new, consistent model of care for adult community specialist palliative care, one that supports people wherever they live in north west London, respects their wishes and helps them stay at home if that is their choice.

Model of care

We are proposing a new model of care for adult community specialist palliative care across north west London. This model is designed to address the inequalities and inconsistencies in the current service offer, and to ensure that every resident, regardless of which borough they live in, has access to the right support, at the right time, in the right place.

Overview of the model

The proposed model is built around the principle of a single, consistent offer of care across north west London.

Care in your own home

Service

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

Key change

7 day service available 12 hours per day in all boroughs 7 day service available in all boroughs Consultant-led advice, available to anyone in all boroughs

Care in a community inpatient setting

Service

Enhanced end-of-life beds

Key change

- Increase beds from 8 beds in Hillingdon to 54 beds across all our boroughs
- Will provide specialist palliative care weekly ward round support in a 24/7 care facility by clinicians and staff with enhanced palliative care skills and knowledge
- Available to patients who do not meet the hospice inpatient bed admission criteria
- 57 beds are needed to meet future need
- Improve access to them by increasing hours in which people can be admitted
- Improving the referral process so it is more clear which patients are eligible for a hospice inpatient beds
- All patients will be able to access any hospice inpatient bed irrespective of where they live in north west London

Specialist hospice inpatient beds

Outpatient and wellbeing care

Service

Hospice multidisciplinary team (MDT) outpatient clinics

Dedicated bereavement and psychological support

Lymphoedema

Key change

Increasing specialist palliative care consultant and practitioner led clinics in all boroughs

A consistent care pathway in all boroughs offering one-to-one counselling and group sessions Expansion of service to care for cancer and non-cancer patients in all boroughs

Key principles

The model is based on five key principles that emerged through extensive engagement and co-design. These are listed below.

- **Equity:** Everyone should be able to access the same high-quality care, no matter where they live in north west London
- **Consistency:** Services should be offered in a coordinated way, with clear service standards and a shared approach across providers
- **Personalisation:** Care should be tailored to individual needs and preferences, with a focus on what matters most to the person and their family
- Integration: Health and social care services should work together to provide joined-up care, including coordination with GPs, hospitals, and voluntary sector partners
- **24/7 access:** People should be able to access specialist support at any time, particularly during evenings and weekends when the current offer can be limited.

Ensuring equity of access

While the proposed model is designed to provide a consistent standard of care across the region, we recognise the importance of local access to services, particularly for bedded care. Wherever possible, we will ensure that services are delivered close to home and reflect the specific needs of local communities and the overall increase in the amount of beds available will help facilitate this.

This is supported by the <u>travel mapping analysis</u> which found that, on average, north west London residents travel around 40 minutes by public transport and 19 minutes by car to reach their nearest inpatient hospice unit. The current suspension of the Pembridge specialist palliative care inpatient unit led to a modest increase in travel times for affected residents, bringing them in line with the times all north west London residents have to travel to hospice inpatient provision now.

Comparison of average travel times

		Average peak time travel Public transport	Average peak time travel Driving
Pembridge Whole NWL catchment population	Travel time to nearest hospice inpatient unit (INCLUDING) Pembridge	40-mins	19-mins
	Travel time to nearest hospice inpatient unit (EXCLUDING) Pembridge	43-mins	21-mins
	Travel time to Pembridge	31-mins	17-mins
	Travel time to next nearest hospice (Pembridge closed)	43-mins	23-mins

Consultation process

A 14-week public consultation ran from 18 November 2024 to 24 February 2025, following extensive pre-consultation engagement since 2022.

Engagement summary

- 84 engagement sessions with local communities, borough forums and faithbased groups
- 10 formal consultation events, including three north west London-wide sessions
- Targeted events for specific communities: learning disabilities, Black African and Caribbean, South Asian, French African, LGBTQ+
- Materials translated and available in easy read and other formats
- Independent analysis of responses commissioned from 3ST, a VCSE sector alliance.

The consultation was an important opportunity to listen to residents and work together to shape the future of healthcare services in north west London. We are grateful for the engagement and thoughtful contributions from the community, which have been instrumental in refining the proposed model of care.

What was consulted on

The consultation tested support for two implementation options, both of which are built around a shared new model of care.

Key features of the new model (both options)

- 12-hour (8am–8pm), 7-day-a-week specialist palliative care community teams in all boroughs
- 24/7 telephone advice and support line, available to professionals, patients and families
- Hospice at Home services expanded across all boroughs
- Specialist palliative care consultant and practitioner led outpatient clinics delivered locally
- Bereavement and psychological support available and consistent
- Lymphoedema care for both cancer and non-cancer conditions
- Culturally competent care, underpinned by staff training and community outreach
- 46 new enhanced –end of life care- beds, in addition to the 8 already available in Hillingdon
- Retain the current 57 specialist palliative care in patient hospice beds.

Enhanced bed provision

 Introduction of 46 new "enhanced end-of-life care beds", based in nursing homes or community settings to support patients who prefer not to be in hospital but cannot or do not wish to remain at home, and they do not require the short, intensive specialist palliative care admission in a specialist palliative care inpatient bed. Retention of 57 existing inpatient hospice beds, considered sufficient for projected population need.

Future inpatient bed base

Borough	Estimated hospice inpatient beds per 100,000 population with current operational beds (57)	Enhanced end-of-life care beds	
Hillingdon	3.28	8	
Harrow	3.08	7	
Brent	2.42	9	
Ealing	2.29	9	
Hounslow	2.29	7	
Westminster		5	
K&C 2.97		4	
H&F		5	
Total no of 24/7 bedded	2.73 average = 57	54	
care			
Total bed base	111		

The introduction of local enhanced end-of-life care beds across north west London, in addition to those already in Hillingdon is a direct response to what residents told us they need, better, more accessible options for those who cannot be cared for at home.

These beds are designed to bridge the gap between hospital and home, offering high-quality palliative care in familiar, local settings. The beds will be provided locally by NHS, charitable or private providers and supported by community specialist palliative care teams and staff with enhanced palliative care knowledge and skills., The addition of enhanced end-of-life care beds respond directly to what residents have told us they need and strengthens our ability to deliver responsive, personalised care closer to home.

Following a long-listing, short-listing, appraisal and assurance process, we consulted on two options:

- Option A (preferred option): Fully implement the proposed model, including 46 new enhanced end-of-life care beds, while maintaining the number of existing hospice beds without reopening the Pembridge Palliative Care Inpatient Unit beds. This option would be easier and quicker to implement and benefit more north west London residents as a whole.
- **Option B:** Fully implement the proposed model, including 46 new enhanced end-of-life care beds and reopen Pembridge Palliative Care Inpatient Unit beds inpatient beds. This would require a reduction in hospice beds elsewhere and have a longer implementation timeline due to the need to recruit specialist palliative care consultant cover and 35 additional staff.

Financial considerations

While both options have been assessed as deliverable, it is important to acknowledge the significant financial pressures currently facing the NHS. A detailed financial appraisal was undertaken as part of the development of the Pre-Consultation Business Case (PCBC). This outlined the overall financial impact and cost difference between Option A and Option B.

- Option A costs £27.6 million
- Option B costs £29.7 million
- The actual cost difference between the two options is £2.1 million.

Option A scored higher in the financial assessment due to it requiring less additional funding than option B and providing the full benefits that are associated with delivery of the new model of care including acute bed days avoided due to people being supported in enhanced end-of-life care beds and avoided hospital attendances and admissions through community services enabling people to die in their place of residence.

However, in a constrained financial environment, Option A presents a more viable way forward because it:

- · requires less additional funding in order to fully deliver the model of care
- enables faster and more equitable implementation across all boroughs by building on current financial and work force arrangements.

In contrast, Option B:

- requires £2.1m additional funding
- significant workforce investment, with past history of ongoing challenge for the Pembridge in patient unit
- significant capital costs of re-opening the Pembridge inpatient unit
- would delay the full rollout of the new model, undermining early benefits.

In addition, implementation of Option B would lead to a reduction in funding to charitable hospices due to the reduction of inpatient beds in these locations. This is important because the financial stability of charitable hospices across the UK has reached a critical point according to Hospice UK, which represents more than 200 hospices; with the sector facing unprecedented pressure. This has been echoed by the four local charitable hospices providing care to north west London residents, advising NHS North West London that their financial positions have worsened since the programme began.

In summary, whilst both options are deemed affordable, Option A provides a more financially sustainable solution that ensures timely and equitable benefits for residents, without compromising the viability of essential hospice or community specialist palliative care based services.

Consultation outcome

An independent analysis of consultation responses by 3ST is underway. The ICB has agreed that it will be finalised following the JHOSC meeting and any subsequent JHOSC submissions. However, themes that have emerged include:

1. Equity of access to services

- A consistent concern across all feedback channels, particularly in boroughs with higher levels of deprivation
- Many participants stressed the need for care to be available closer to home, citing difficulties with travel, especially for those with mobility issues or limited financial means
- Some correspondents were concerned that access to hospice inpatient beds would worsen in some boroughs if Pembridge did not reopen.

2. Strengthening community and home care services

- Strong and widespread support for improving home-based palliative care, including 24/7 services and culturally responsive provision.
- Many respondents welcomed investment in this area, regardless of their view on inpatient provision, highlighting a preference for care in familiar environments where possible.

3. Need for local inpatient services

- While views varied on how inpatient care should be configured, many participants emphasised the need for local availability and welcomed the introduction of enhanced end-of-life care beds.
- Many participants expressed the view that Pembridge inpatient unit was an important local resource and should reopen
- Others acknowledged the practical challenges of reopening any facility.

4. Workforce capacity and feasibility

- Some respondents, especially professionals, raised concerns about the feasibility of implementing expanded services without affecting stability in existing hospices
- This was particularly relevant to proposals involving recruitment of additional specialist staff to support any increase in inpatient provision including any potential reopening of Pembridge Palliative Care Inpatient Unit.

5. Cultural competence and inclusive services

- Strong messages from ethnic minority communities stressed the importance of culturally sensitive care—whether in the home, hospital, or inpatient settings.
- Respondents wanted reassurance that care would be respectful of diverse languages, faiths, and beliefs.

6. Continuity and familiarity of care

- For all, familiarity with existing services, including community teams and their local hospice inpatient unit was a key factor in shaping preferences
- Respondents described comfort and reassurance in known facilities and staff, especially where continuity of care could be maintained.

8. Service design clarity: enhanced end-of-life beds

- Some requested more detail on what enhanced end-of-life beds would offer, how they would be staffed, and how the public would access them.
- There were calls for clearer definitions and practical information.

The most significant themes raised in the consultation were:

- 1. **equity of access**, particularly concerns from deprived and inner-city areas about travel distances and care availability;
- 2. **desire for stronger community-based and home services**, with high support for expanding care closer to where people live;
- 3. **the importance of local inpatient care**, including support for introduction of enhanced end-of-life care beds.

There was strong support for the full introduction of the model of care including enhanced end-of-life care across all boroughs in north west London. Support for Option A was strongest in outer boroughs where they were not concerned about the future of the Pembridge inpatient unit and felt that equity of provision was more important. Support for Option B was strongest in inner boroughs where some expressed support for the reopening of the Pembridge inpatient unit.

Other important themes included workforce capacity, transparency in planning, culturally appropriate care, and continuity for families and carers.

Due to delays in agreeing the formal scrutiny process for the consultation options, NHS North West London had extended the deadline for any response from local government to 30 April, 2025. Given that it has now been agreed to discuss the meeting at the JHOSC meeting on 1 May 2025, we are able to offer a final deadline for response of 15 May 2025.

What is happening now

While no final decisions have been made, we have begun working with NHS and charitable hospice partners at borough level to hold initial planning discussions to explore how the new model of care could be implemented. This includes identifying who is best placed to deliver different elements of the model and considering where services could be located. Local planning is split into four areas, each with assigned leads.

- Brent and Harrow is being led by Lindsey Bennister (St Luke's Hospice) and a place based co-lead is to be confirmed. The initial planning workshop is scheduled for 20 May 2025.
- Ealing and Hounslow leads are to be confirmed and the initial planning workshop is in the process of being scheduled.

- Hillingdon is being led by Jane Wheeler (Harlington Hospice). This will be absorbed into an existing palliative care transformation programme so a separate planning workshop is not required.
- West London, Central London and Hammersmith & Fulham is being led by Emily Carter (Royal Trinity Hospice) and Navneet Willoughby (CLCH). The initial planning workshop took place on 26 March 2025.

Early planning discussions are focused on identifying local needs, addressing service gaps, and exploring potential delivery options. Once a final decision on the consultation outcome has been made, we will begin a more detailed appraisal of options and support the development of tailored implementation plans for each area.

For instance, Central London Community Healthcare NHS Trust, the current provider at Pembridge, has expressed interest in delivering the proposed enhanced end-of-life care beds for Hammersmith & Fulham, Kensington and Chelsea and Westminster and we will be exploring with them whether these could be provided from existing NHS estate.

The high level timelines for the implementation planning are:

- March July 2025 Initial workshops and pre-planning of services.

 Determining what needs to be done to bring services in line with the new model of care for each local area and exploring possible delivery options.
- **July 2025 –** Confirmation of final consultation outcome and business case decision on funding.
- August 2025 October 2025 Detailed appraisal of options for service delivery and operational planning to develop plan for phased implementation of services over 2 years.
- October 2025 New contracts begin and phased implementation of services commences.



We are also progressing work on the five enablers that will underpin delivery of the new model of care. A reducing inequalities working group has been established, and alongside this, a community reference group is in place to guide and support the work on tackling inequalities, bringing in diverse voices and lived experiences.

In terms of digital and data enablers, we are continuing to expand the use of the Universal Care Plan and improving our data collection capabilities. This will allow us to monitor services more effectively and use data to inform continuous improvement.

Work is also underway to bring providers together to deliver the workforce development enabler through a collaborative, pan-north west London approach.

Next steps

A Decision-Making Business Case (DMBC) will be presented to NHS North West London Board, with a final decision expected by summer 2025. Contract extensions for charitable hospices have been agreed to ensure that current CSPC services continue until the end of September 2025. It is planned that implementation of the new model will begin in autumn 2025, on a phased basis across boroughs.