



**North West London  
Integrated Care System**

Working together for better health and care

# **Community-based specialist palliative care improvement programme**

**North West London Joint Health Overview Scrutiny Committee**

**March 2024**

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

Over the last few months we have been working to get to a place where we can now publish the [revised NW London model of care for community-based specialist palliative care for adults \(18+\)](#). At the same time we have also looked at how we can best deliver the new model of care and this has led us to a potential shortlist of five implementation options.

This involved a lot of engagement events and conversations and we are incredibly grateful to all our patients, families and carers and wider stakeholders including our partner hospice providers, both NHS charitable and NHS, for their feedback, comments and support. We would have not got to this stage without you.

The revised version of the model of care has been greatly strengthened because of the feedback given by residents, health professionals and a broad range of local stakeholders at engagement events and in written comments following the release of the first version of the model of care in August 2023.

Overall there was good support for the proposed new model of care. People liked that we want to increase the amount of support available in the community to help people stay in their own homes. They also liked the almost doubling of the number of beds to over 100 available to support local residents who either need the intensive support provided by a hospice inpatient bed or the less intense but also vital enhanced end-of-life care bed that will be available to those people who sadly are not able to stay in their own home. However, we did hear some valuable challenges and constructive suggestions on how we might improve the model of care and these are reflected in this revised version.

We have also published:

- [A report on the engagement undertaken in September and October 2023](#)
- [A paper covering the refreshed 10-year demand projections for hospice in-patient care](#)
- [An Equalities Health Impact Assessment \(EHIA\) report](#) which explores the potential impact that NW London's proposed new model of care will have on health inequalities and the well-being of different population groups in NW London.

In November and early December 2023 we held eleven engagement events, [which are all viewable on our website](#), with local residents where we jointly looked at all the options for how we could deliver the model of care. We have now published an [options engagement outcome report](#) which describes the process that was followed to reach the potential five shortlisted options for delivery of the model of care.

These shortlisted listed options are:

- Option 0 – do nothing, continue with current provision.
- Option 1 – some change, minimum workable solution with a focus on providing fairness of provision (minimal improvement to care in the home, Pembridge in-patient unit remains closed, 54 enhanced end-of-life care beds).

- Option 2 - some change, minimum workable solution with a focus on providing fairness of provision (minimal improvement to care in the home, Pembridge in-patient re-opens, 54 enhanced end-of-life care beds).
- Option 3 – full implementation, fully deliver model of care (substantial improvements to care in the home and other community-based specialist palliative care services, Pembridge in-patient unit remains closed, 54 enhanced end-of-life beds).
- Option 4 – full implementation, fully deliver model of care (substantial improvements to care in the home and other community-based specialist palliative care services, Pembridge in-patient unit reopens, 54 enhanced end-of-life beds).

We are now working through a detailed non-financial and financial appraisal process, and engaging with the London Clinical Senate and NHS England on their assurance processes which are part of a proposed service reconfiguration. This will take a number of months before any final decision is made on how we move forward. If it is decided that we need to consult on any potential service change is likely to take place following the London Mayoral election that will take place on 2<sup>nd</sup> May 2024.

We will provide another progress update soon but please do [contact us](#) in the meantime if you have any comments or questions on the revised model of care or other publications.

### **Revised new model of care for adult community-based specialist palliative care services published**

Following the release of the initial proposed model of care in August 2023, we undertook an extensive period of engagement to hear the views and receive the feedback of our residents, health professionals and a broad range of local stakeholders.

A series of nine engagement events took place in September and October 2023 at which attendees had the opportunity to learn more about the model and comment on the proposals. We also received feedback via online surveys, email and in other face-to-face meetings.

Overall, there was good support for the proposed new model of care. 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:

- Further information on the proposed enhanced end-of-life beds.
- Addressing inequalities and disparities in access, outcomes and experiences of palliative care services.
- Enhancing innovation and continuing to make improvements to specialist palliative care services alongside the implementation of the new model of care (including service navigation and co-ordination).

- Improving leadership and governance.

The revised new model of care features extensive changes to reflect these points. There are also various other more minor revisions and additions to reflect other points raised during public engagement.

The revised new model of care also features a full statement explaining these changes and highlighting of them within the document.

The revised model can be seen [here](#) on our website.

### **Our work with charitable and NHS providers to develop and take forward the model of care**

We are 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 also like to again thank the providers and clinicians who have engaged with us on model of care discussions, bringing their years of experience and knowledge to the steering and working groups and the public engagement events on the model.

In particular, we would like to thank our eight 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 \(LNWH\)](#)

### **Engagement report on the model of care (September-October 2023)**

We have published a model of care engagement report covering the comments and feedback received at the eight engagement events held at both a NW London and borough level in September and October 2023 and through an online survey and written submissions.

The engagement events were attended by residents, community-based specialist care provider leads, voluntary sector, borough programme leads and other key stakeholders and the attendees had the opportunity to provide feedback, ask

questions and put forward their own suggestions of potential options to be considered if they thought we had missed or omitted anything

We obtained a rich amount of feedback, comments and valuable input regarding the proposed new model of care and wider palliative care improvement which is detailed in the engagement report.

We found that attendees were broadly supportive of the proposed model of care but there were several areas where they asked for further information or suggested the model needed strengthening and this feedback has informed the [revised model of care](#) we have just published.

The model of care engagement report can be found [here](#).

The notes of the meetings are included within the report and are also available, along with videos of the meetings, via the events page [here](#).

### **Engagement outcome report on potential delivery options for the new model of care (November-December 2023)**

At the start of November 2023 we were ready to look at what implementation of the new model of care could mean in practice and wanted to ask our local residents for their thoughts on future potential delivery options for the model.

In late November and early December 2023 we completed eleven engagement events where we looked at potential options and attendees had the opportunity to provide feedback and ask questions and also had the opportunity to put forward their own suggestions of potential options to be considered if they thought we had missed or not thought of something.

This included three NW London wide engagement event and one for each of the NW London boroughs. In addition to this we completed a second engagement event for Hammersmith and Fulham borough at the request of residents and the local authority.

These engagement events were attended by residents, community-based specialist palliative care provider leads, voluntary sector, borough programme leads and other key stakeholders. At the events we explained the process we followed for developing all the options and how we had used hurdle criteria agreed by the Community-based Specialist Palliative Care Steering Group to whittle these down to a short list of five potential delivery options.

The four hurdle criteria we used were:

- Strategic fit - how well the option advances local, NW London, regional and national priorities (specifically whether the service proposal reduces inequity of provision across NW London and meets evidence of need).

- Quality of care - how well the option improves the service delivered to residents and outcomes (specifically whether the proposed service configuration leads to safe, high quality care and accessible care).
- 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 (i.e. whether the proposal can be realistically delivered).

The five short listed delivery options are:

- Option 0 – do nothing, continue with current provision.
- Option 1 – some change, minimum workable solution with a focus on providing fairness of provision (minimal improvement to care in the home, Pembridge in-patient unit remains closed, 54 enhanced end-of-life care beds).
- Option 2 - some change, minimum workable solution with a focus on providing fairness of provision (minimal improvement to care in the home, Pembridge in-patient re-opens, 54 enhanced end-of-life care beds).
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- Option 4 – full implementation, fully deliver model of care (substantial improvements to care in the home and other community-based specialist palliative care services, Pembridge in-patient unit reopens, 54 enhanced end-of-life beds).

We obtained a rich amount of feedback, comments and valuable input regarding the proposed new model of care and wider palliative care service improvement.

We found that there was a broad consensus amongst attendees on the proposed five shortlisted service delivery options for the new model of care that were presented.

The full engagement outcome report on potential delivery options for the new model of care is available [here](#).

### **Equalities Health Impact Assessment (EHIA) on the proposed new model of care**

The Equalities Health Impact Assessment (EHIA) report explores the potential impact that NW London's proposed new model of care for adult (18+) community-based specialist palliative care services will have on health inequalities and the well-being of different population groups in NW London.

This report is intended for a broad audience, encompassing healthcare professionals, stakeholders and advocates for palliative care, and the communities and individuals that this new model of care aims to serve.

The report provides an overview of the NW London health inequalities landscape and explores the EHIA process for the nine protected characteristics, and other vulnerable groups that we have identified as key during our engagement, to provide a summary of equity impact.

Our goal is to make sure that this new model of care and way of providing care is fair and equal for everyone, giving help and support without any bias.

The EHIA on the proposed new model of care can be viewed [here](#).

A further EHIA will be carried out on the proposed short-listed options.

### **Refreshed ten-year demand projections for hospice in-patient care**

In 2023 we created a data pack showing demand and capacity data modelling to inform our thinking on the number of hospice beds required to support the needs of NHS NW London for the next five years.

The data was released alongside the model of care and we subsequently engaged with local residents and stakeholders on the proposals in September 2023.

As part of this engagement, there were three specific points raised in relation to the data:

- Are beds evenly distributed to serve our borough populations?
- Have we used a consistent approach to measuring bed capacity?
- How does use of 2023/24 data affecting our modelling?

What has changed (and is reflected in this new updated paper) since the original data publication:

- We know at a borough level that the majority of residents are evenly served by the current 57 operational beds. The south of Hillingdon being the exception to this.
- We have 57 hospice in-patient beds instead of 56. The difference is the result of measuring capacity consistently across all beds, including spot purchasing arrangements.
- Greater variation in use of hospice in-patient beds in 2023/24 means we have considered a range within which we expect demand to present. At the upper end of our modelling, we would expect to have sufficient hospice bed capacity to meet our needs until 2027/28.

The new updated data paper can be viewed [here](#) on our website.

### **Directory of services for North West London**

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, which can be found here: <https://hpal.medindex.co.uk/p/t/palliative-care/services>

This website, funded by Harlington Hospice, has been designed to enable patients, carers and clinicians to search for palliative care services and resources across NW London and within each borough.

## **Advance care planning (ACP) and the Universal Care Plan (UCP)**

The importance of advance care planning (ACP) was highlighted in the development of the model of care and public feedback during engagement on the model. 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.

NW London residents can have their care preferences made known and shared with the health and social care system via the [Universal Care Plan \(UCP\)](#).

From January 2024, all patients with a UCP are now able to view it on the NHS App. This development will increase visibility of patients' wishes and preferences, and improve transparency between clinician, patients and carers.

A communications resource pack for clinicians that further explains this change can be downloaded here:

[UCP NHS App Integration Resource Pack January 2024.pptx \(live.com\)](#)

## **Pembridge Palliative Care Services**

This Pembridge Palliative Care Services in-patient unit has been suspended for use since the end of 2018 as a result of the inability to recruit and retain specialist palliative care consultant cover required to safely run the unit.

All other Pembridge Palliative Care Services (ie. 24/7 specialist telephone advice line, community specialist palliative care nursing and therapy teams and other services) are unaffected and continue to operate.

NHS NW London has not made a decision to permanently close the Pembridge inpatient unit site and, together with the Central London Healthcare Trust (CLCH) who provide the service, are open to recruiting the specialist palliative care consultant to support the safe reopening of the in-patient unit.

We have heard there is still a strong desire for the Pembridge in-patient unit to be reopened and that options from the public for how we could reopen the unit could be more widely considered than they have been to date.



We have arranged two meetings over the last few months with patient representatives, CLCH and Imperial College Healthcare NHS Trust (ICHT) to discuss options for re-opening the in-patient unit. It was agreed that ICHT and CLCH would meet to discuss whether and how the two services could work together in a more integrated manner to support re-opening the in-patient unit in future with a more robust and resilient staffing model and whether joint recruitment to posts at Pembridge may be possible.

In the meantime, CLCH have successfully recruited to a fixed term contract post for a specialist palliative care consultant to oversee Pembridge day services and community team services. The recruitment of a specialist palliative care consultant to support the Pembridge in-patient unit is waiting the next stage of the interview and recruitment process.