

## **Communication and engagement strategy for the public consultation on the new North West London model of care for community-based specialist palliative care services**

### **1. Introduction**

#### **1.1. About the North West London model of care for community-based specialist palliative care services**

In 2021 we began a journey to review and shape the future provision of adult (18+) community-based specialist palliative care services in North West London (NW London) with the publication of an **Issues Paper** that set out why we were looking at a service that is so important to patients, families, carers and friends at a time of their greatest need.

Our ambition is to develop services that are patient-centred and provide choice, focusing on tailoring services and treatment plans to meet the individual needs and preferences of each patient.

Since then we have focused our review programme's work on building a new model of care that will deliver equal access to high quality community-based specialist palliative care (CSPC) and end of life care and support that is coordinated, and which from diagnosis through to bereavement reflects the individual needs and preferences of NW London residents, their families, carers and those important to them. We also want to ensure that any proposed new service provision is sustainable and that we can continue to deliver the same level of high quality care in the future.

Our ambition is to develop services that are patient-centred and provide choice where it is available. There will be a focus on tailoring services and treatment plans to meet the individual needs and preferences of each patient. We recognise that healthcare should not be a one-size-fits-all approach and that people have unique health conditions, values, and goals.

#### **1.2 Developing the new model of care**

We recognised from the very start that the success of the programme would rely on working closely with local residents, families and carers. Over the past three years, we have carried out extensive engagement and made adjustments to our proposals based on feedback received. The revised model of care reflects these inputs and aims to provide high-quality, equitable services across all boroughs.

#### **1.3 Strengthening engagement for better public involvement**

Following the beginning of our review work in 2021, we carried out extensive engagement with local residents, and in June 2022 we published an **interim**

**engagement outcome report**, followed by a **final engagement outcome report** in March 2023.

The feedback and information received fed directly into [the model of care working group](#) who had responsibility for developing and co-designing the new model for community-based specialist palliative care in north west London.

The working group consisted of north west London residents with lived experience of palliative and end-of-life care, as well as bereavement, along with clinicians and providers. Over a twelve-month period, the group met over thirty times to consider the evidence and best practice, systematically co-design the services and support the development of a new, improved model of care

The **initial version of the model of care** was published in August 2023 and we then engaged with north west London residents, health professionals and a broad range of local stakeholders to test whether the model was fit for purpose or if there had been things that we had missed or needed to strengthen.

From September 2023 to October 2023 we completed eight engagement events at both a NW London and borough level, as well as briefing councillors from each of the eight boroughs. These engagement events were attended by residents, CSPC provider leads, voluntary sector, borough programme leads and other key stakeholders. 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 covered in this **engagement report**.

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.

This feedback was then reflected in a [revised NW London model of care for community-based specialist palliative care for adults \(18+\)](#), greatly strengthening the proposal.

#### **1.4 Options for delivery of the new model of care**

At the same time as revising and strengthening the proposed model of care, we also looked at how we could best deliver the new model.

We considered the widest possible set of scenarios for how the model of care could be delivered and identified 54 possible delivery options. We then applied four hurdle criteria (strategic fit, quality of care, affordability and achievability), developed by the [NW London CSPC steering group](#), to reduce possible potential options to a manageable set of choices that we could examine in more detail.

This led to a shortlist of five implementation options:

- Option 0 – do nothing, continue with current provision (no change).

- 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).

In late November and early December 2023 we asked our local residents and stakeholders for their thoughts on these potential delivery options for the model. We undertook eleven engagement events at which we discussed the shortlisted options and attendees had the opportunity to provide feedback, ask questions and put forward their own suggestions on potential options to be considered, if they thought we had missed or not thought of something.

We obtained a rich amount of feedback, comments and valuable input regarding the proposed new model of care and wider palliative care service improvements. We found that there was a broad consensus amongst attendees on the proposed five shortlisted service delivery options for the new model of care. The feedback and further detail on the process is provided in the [options engagement outcome report](#).

Since then we have worked through a detailed non-financial and financial appraisal process and progressed through the London Clinical Senate, NHSE and ICB approval processes, as well as engaging with the Mayor of London's office.

## **1.5 Public consultation**

We are now formally proposing that we consult on two of the shortlisted options (options 3 and 4). These options scored highest in our assessment, both individually in the non-financial and financial assessments and collectively.

We believe that 'do nothing' (options 0) and options for partial implementation of the new model of care (options 1 and 2) will not deliver the ambition we have for North West London residents. We are providing information on these options within the consultation for information and to inform feedback rather than as proposed options that we are formally consulting on.

No decisions have been or will be made on options until further engagement has taken place and NHS NW London are receptive to receiving feedback on all options that we can consider.

Further detail on our work on the options is will be detailed in Pre-Consultation Business Case that will be published when the consultation is launched.

## **Next steps following this consultation**

Once the public consultation closes, all feedback and responses received will be collated and analysed by [3ST](#), a charitable organisation and alliance of voluntary and community sector organisations working across north west London,

This will be incorporated into a post-consultation report which will be published on the NHS North West London website [www.nwlondonicb.nhs.uk/cspc](http://www.nwlondonicb.nhs.uk/cspc).

In determining the agreed option for implementation of the new model of care for adult community-based specialist palliative care, NHS North West London will consider the outputs from the public consultation and use this to inform the final decision.

No decisions about any changes to services will be made until after the full public consultation has taken place and all of the information, including the feedback from the consultation, has been considered.

## **2. About this communications and engagement strategy**

### **2.1. Objectives**

This strategy is designed to support the public consultation process on the proposed model of care for community-based specialist palliative care services in NW London for adults (18+).

The objectives of this strategy are:

- To gather feedback from local residents, stakeholders and staff, making it as easy as possible to comment through a choice of channels and reaching out effectively to ensure people are aware of the consultation and how they can contribute
- While retaining flexibility for how people can participate and valuing all contributions, aim to secure feedback about both of our preferred consultation options – relevant to views on their respective strengths and weaknesses, how they will impact on services and service users, and issues relevant to implementation
- Secure a mix of both quantitative feedback (e.g. through a questionnaire) and qualitative feedback (e.g. through noting discussion at meetings) to develop insight into participants' views which are as rich and detailed as possible
- Where rooted in the data, indicate where there is majority agreement and where there are differences of view held by different groups
- Meeting statutory duties, ensure that inclusion in the consultation process is as broad as possible and that those individuals and groups most likely to be impacted by the service change are fully engaged and their voices are particularly clearly heard
- Capture all feedback from the consultation within a single analysis and report to enable the NHS North West London decision to be fully informed.

### **2.2. Governance, duties, and relevant guidance**

This Strategy is designed to comply with:

- The statutory duty to involve the public and consult on proposals to develop NHS services – National Health Service Act 2006 (as amended)
  - s14Z45 (ICBs), s242 (Trusts), s244/245 (Health Scrutiny)
  - B1762 Working in Partnership with People and Communities Statutory Guidance (NHSE, July 2022) (See summary at Appendix A.)
- Equality Act 2010
  - s149 public sector equality duty
  - Other obligations including duty to reduce inequality
- The Government’s four tests for NHS service change (specifically the first test: strong public and patient engagement)
- Gunning Principles for public service consultations:
  - Proposals are still at a formative stage
  - There is sufficient information to give ‘intelligent consideration
  - There is adequate time for consideration and response
  - ‘Conscientious consideration’ must be given to the consultation responses before a decision is made.

The Mayor of London’s six tests for NHS service change, specifically test six - patient and public engagement - proposals include meaningful patient and public engagement, including with marginalised groups, in line with Healthwatch<sup>1</sup> recommendations.

### **2.3. Development and responsibility for this strategy**

This strategy has been developed by NHS NW London. The consultation will be delivered according to these principles:

- Through a structured process, with shared management across the system to ensure that the consultation aligns with other strategic programmes in NW London
- Working at place/borough through and with existing engagement and partnership structures
- Working in partnership with the charitable and NHS palliative care providers
- Through the wider network of NHS, local authority and community and voluntary sector groups
- Encompassing both communications and engagement – to ensure that people are able to find out about the consultation and how to participate, those likely to be particularly impacted are reached through a range of relevant channels, and comments and feedback are considered in depth

## **3. About the consultation**

As part of our commitment to ensuring that every voice is heard, we are enhancing our approach to engagement to make it even more inclusive and meaningful for all residents in North West London. We recognise that different groups of people have different needs. To make sure we hear from a wide range of voices, we will proactively reach out to specific communities, such as older people and ethnic minority communities. This will allow us to gain deeper insights into what matters most to people with different lived experiences.

### **3.1 Information**

There will be a variety of information made available to inform participants and enable them to make meaningful comments. This will be hosted on the ICB website, and include the pre-consultation business case, core consultation information including the main consultation document, a summary version and an easy read version. In addition, it will include:

- A summary of the case for change and current service configuration
- The consultation options
- Information about the process so far and how the model of care was developed
- How to contribute views, including a schedule of events?
- Next steps following the consultation
- How to obtain materials in accessible formats?
- Detailed background documents, including the Equalities Health Impact Assessment, the updated model of care
- A white board animation that explores the patient journey
- Video updates

We will also provide support for those who may need some additional help to participate, including translations, different versions of the consultation document (e.g. printed, audio, large print, Braille) and tailored support to participate if, for example, a person has a learning disability or difficulty in communicating.

### **3.2. Equalities groups and communities**

The Equality Act identifies nine protected characteristics and public service providers are required to ensure that action is taken to tackle discrimination against people sharing these characteristics and, where service changes are planned, that disproportionate impacts against people sharing these characteristics are considered and mitigated where possible:

- Age
- Disability
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation.

The equality health impact assessment indicates the proposed model of care will be positive for people whose characteristics are age, disability and religion or belief and neutral for people with the other characteristics.

The assessment also identifies additional vulnerable groups for our work, specifically:

- Carers
- Single person households
- Deprived populations
- People living in sub-standard accommodation

- Homelessness
- Mental health and dementia

Populations with these characteristics have been identified through our engagement activities as particularly important for this work. They have therefore been included to ensure that our proposals consider the specific circumstances of people who are most likely to be impacted, and that any negative impacts are either avoided or appropriately mitigated.

The equality health impact assessment describes the impact on people with protected characteristics but we also indicate the proposed model of care will be positive for carers, single person households, deprived populations, people living in sub-standard accommodation and homelessness and neutral for deprived populations and those with mental health and dementia.

As we move forward through the consultation, we will continue to update the equality health impact assessment to inform any potential decision that NHS North West London makes.

### **3.3. Local population**

The proposed model of care covers the whole of NW London so the consultation will aim to encourage responses from the local populations in each of the boroughs, working with local partners and stakeholders.

### **3.4. Priority groups for consultation - equalities**

As required by law, the key groups for consultation are:

1. Users, or potential users, of community-based specialist palliative care services in NW London
2. Users, or potential users, sharing protected characteristics under the Equality Act (or otherwise at risk of health inequality) who may be disproportionately impacted by the proposed changes.

Following an equality health impact assessment, integrated impact assessment and a review by the Clinical Senate, the following groups have been identified as the highest priorities:

- Residents of NW London
- Those populations who are under-represented in access to adult community-based specialist community palliative care services, including BAME residents and younger people.
- People in those wards with most limited geographical access to services and have longer travel times.

### **3.5. Other groups for consultation – residents, service users and their families, carers and those important to them, stakeholders and staff**

In addition, other groups we would prioritise for engagement include stakeholders, and local organisations, plus networks and media who will carry information about the consultation. These include:

- Anyone who is currently using community-based specialist palliative care services in NW London
- Families and carers of people who use, have used, or might use community-based specialist palliative care services
- Professional representative bodies such as local medical committees
- Community representatives, including the voluntary and faith sector
- Local authorities
- Health and social care partners including: charitable and NHS providers of palliative care, primary care, acute hospital
- Community and mental health services
- Individuals and groups we have previously engaged with during the development of the model of care.

### **3.6. Promotion of the consultation**

The consultation questionnaire and schedule of engagement activities will be publicised through a variety of channels:

#### Owned

- Existing contact lists of service users, stakeholders and residents who have signed up to receive more information about the review of community-based specialist palliative care services and/or health services made widely
- NHS North West London and partner social media channels (X, Instagram, Facebook and Next Door), websites, newsletters and engagement channels (e.g. mailings)
- NHS North West London and review programme key stakeholder and partner contacts
- North West London and borough end-of-life groups and contacts

#### Borrowed

- Cascade of information through community organisations/local partners/borough contacts
- Local authority channels website, social media and/or newsletters

We welcome opportunities raised by partners and stakeholders to support engagement and consultation with our residents.

#### Bought

- Advertising through social media and meta channels

### **3.7. Responding to the consultation**

The review website and consultation documents will provide clear information on how NW London residents and stakeholders are welcome to respond, and we are committed to ensuring that it is as easy as possible to comment, through a variety of different channels which both make the process as accessible and inclusive as possible, and also actively seek the views of those priority groups set out in this strategy.



This includes actively reaching out through local groups and networks to promote the consultation and offer speakers to attend meetings.

Channels are expected to include:

- Questionnaire linked to on the ICB website with both quantitative and free text questions and the opportunity to make more general comments relevant to the consultation, along with demographic and other monitoring questions to facilitate analysis of different groups' (e.g., by area of residence, service use, demographic characteristics)
- Print copies of the questionnaire, which will be transcribed for analysis
- Correspondence by post (consultation/team mailbox), or email (consultation/team inbox)
- Shared through social media feeds
- Actively shared through the NHS NW London borough networks
- Face-to-face and online at public meetings (open access)
- Face-to-face or online meetings (focus groups and/or 1:1 depth interviews) by invitation with specific groups (e.g. staff, service users, residents, representative groups)
- Community outreach – members of the programme team attending meetings and local open forums to provide information about the consultation, promote and distribute forms and answer questions (where possible these meetings will be noted and comments included within the analysis).

Respondents will be able to use NHS North West London freepost address to respond to the consultation.

### **3.8. Consultation meetings and activities - report – Keeping you informed**

We will provide a clear update to show how your feedback is shaping our decisions. We will share the analysis, reports, and key findings to make sure you stay informed about how your contributions are making an impact.

The consultation public meetings and events will comprise a range of activities:

- Clinician and director-led, open public meetings – deliberative methodology
- Drop-in engagement sessions – to answer questions and distribute questionnaire
- Community outreach events – attending events hosted by community organisations
- Writing to local community organisations – to promote the consultation and offer speakers
- Proactive reach out to arrange focus groups / in-depth interviews – with identified equality groups and those with whom we have previously engaged

### **3.9. Consultation analysis and report**

All feedback received through all the channels set out will be considered in a single analysis. It will also include any formal submissions from stakeholder groups and organisations.

We have appointed [3ST](#), a charitable organisation and alliance of voluntary and community sector organisations working across north west London, to carry out this analysis and produce a report.

The consultation report will summarise:

- The consultation responses
- Views on the preferred option, highlighting where justified by the data differences of views between different groups
- Analysis of comments more broadly relevant to the proposals, such as views on the clinical model and issues for implementation of option(s).

The report will be published, form an appendix to the decision-making business case (DMBC), and be formally considered by the ICB.

Through this process, thematic responses which challenge the preferred option, the proposed model and/or the assumptions underpinning these will be highlighted so they can be taken into account during development of the DMBC and the final decision(s) taken by the ICB.

Any strengths identified in other options, provided as comparators, will be considered to see if they can be incorporated into the final selected option.

## Appendix A: Working in Partnership with People and Communities Statutory Guidance (NHSE, July 2022)



*B1762 Working in partnership with people and communities: statutory guidance NHS England (2022)*

## **Appendix B Consultation communication and engagement plan**

Consultation on the future of community-based specialist palliative care services for residents of NW London

### **1. Consultation activities**

A range of meetings and events are being planned during the consultation period, using different formats as set out below. In order that these are as inclusive as possible, we note:

- Interpreting support/translators may be required
- Promotion must use a range of channels, including accessible formats.

#### **1.1. Public meetings**

Central to the consultation will be structured engagement meetings and events open to all – both face-to-face and online. The two main formats proposed are tried and tested in consultations across London and for this review programme. They are designed both to inform people about the proposals and gather views, and to provide a forum for broader engagement by the NHS in North West London.

##### **1.1.1. Open public meetings**

- Structured discussion to gather views and feedback using deliberative methodology.
- Including information on the proposals, opportunities to question and challenge, public discussion with notes taken and all comments considered within the consultation analysis.
- A minimum of one public meeting in each borough. These meetings will also be open to all NW London residents but each borough specific meeting will be targeted particularly at residents and stakeholders from that borough.
- A number of NW London-wide events.
- Recruitment to the events will be undertaken using existing channels and local promotion, with registration of people signing-up.

##### **1.1.2. Drop-in engagement sessions**

- Drop-in sessions at various locations across all eight boroughs with consultation documents available and support to consider and complete the questionnaire.
- NHS North West London staff available on location to answer questions and support members of the public with questionnaire.
- Sign-up not requested.

### **1.2. Community outreach**

We recognise that North West London is home to a mixed and culturally diverse community, and we have residents with a wide range of backgrounds, needs and experiences. They are supported, represented, and brought together through a rich ecosystem of third sector providers, community groups and representative associations.

Through a programme of community outreach, we will aim to engage individuals and groups who may be traditionally less engaged; face access issues, experience inequality or have additional needs; or who may be especially affected by the proposed service changes. This will draw heavily on local relationships maintained by NHS NW London and its partners. It will rely on working through trusted networks and intermediaries, which experience tells us is the best way to reach out.

### **1.2.1. Community outreach events**

We will work with the ICB Borough teams to develop an approach which identifies and seeks invitations to attend existing meetings and events:

- Slots incorporated into existing engagement/outreach activities/events
- Communications and engagement staff available to answer questions, encourage response and/or support completion of questionnaire
- Particular focus on targeted groups and geographic locations.

### **1.2.2. Writing to local community organisations**

To maximise access to the consultation, we will also write to the ICB database of local community organisations:

- Provide information about how their members and users can participate.
- Offer information and provide a speaker at events.
- Provide materials on (e.g. weblinks and leaflets for distribution).

### **1.3. In-depth interviews**

We have previously conducted a number of [in-depth interviews with individuals and representative organisations](#) during the development of the model of care.

We aim to revisit these contacts, update them on the proposed changes and seek their views.

We also aim to reach out to the priority groups identified in 3.4 and 3.5 and seek in-depth conversations and interviews.

## **1.4. Timing**

Subject to necessary approvals, the consultation is expected to begin during the week commencing 18<sup>th</sup> November 2024 and is scheduled to run for a minimum of 14 weeks (allowing two weeks for the Christmas and New Year period).

## **1.6. Complaints, queries, and information requests**

There will be a daily monitoring of the consultation/team inbox, social media feed and consultation responses to ensure responsive action can be taken as required. The consultation/team email will be included on all consultation materials so that people have an accessible, standard way to contact the consultation team. All communications will be directed to the central consultation/team email inbox to enable the team to respond to queries and requests efficiently.

## **1.7. On-going monitoring and interim headline review**

This consultation and engagement strategy will be monitored on an on-going basis to ensure that activities outlined are gaining maximum reach. The team will undertake regular review and adapt plans to reflect any issues raised or identified.

The team will also conduct an interim headline review during week eight covering both quantitative survey data and qualitative comments received up to that point.

The purpose of this review will be to:

- Identify key emerging themes in the feedback in order to establish whether additional analysis or development is required for consideration of any of the options.
- Identify any groups not satisfactorily engaged or gaps in the feedback gathered, and to inform additional engagement activity required.
- Identify any issues arising that require responsive actions during the remaining consultation period.

## **1.8. Briefing political stakeholders**

Political stakeholders will be offered:

- A briefing on the consultation before launch, so they are informed and sighted on plans before publication of the PCBC and materials.
- Opportunities for ongoing contact according to their preference (e.g. named contact person, regular update emails, attendance at events).

The key political stakeholders in scope for this part of the plan are:

- Joint Health and Overview Scrutiny Committee
- Local Authority cabinet members and officers in NW London
- Members of Parliament in NW London constituencies
- London Mayor's Health Adviser (Dr Tom Coffey).

NB: Local authority cabinet members and officers in NW London have been engaged throughout the development of the model of care and the team will attend any appropriate scrutiny meetings, including JHOSC, during the consultation period to brief members and answer questions.

### **1.9. Launch plan**

In order to focus attention on the consultation and promote participation, a public launch will be led by the NHS North West London Communications and Engagement Directorate. This will comprise:

- Launch of consultation website pages including launch video and event
- Widespread communication through all social media channels
- Issue of programme newsletter to all stakeholders
- Widespread communication via partner channels
- News release
- Interview offered with key clinician

### **1.10. Ensuring reach to seldom heard groups and those facing inequality**

We will identify community and grassroots groups supporting residents with protected characteristics and/or part of the priority groups identified in the equalities impact assessment.

Targeted work is underway and will continue throughout the consultation to gather the views of people from these groups. We intend to do through partnership engagement activities with identified community groups and community representatives, undertaking one to one interviews (where appropriate) and outreach.

### **1.11. Response channels**

We want to hear from as many people as possible - patients, families, carers, members of the public, staff, voluntary sector representatives and advocates as well as partners are all encouraged to respond to the consultation.

People can respond to the consultation in a number of ways including:

#### **By completing the public consultation questionnaire**

The online questionnaire will be available at: [www.nwlondonicb.nhs.uk/cspc](http://www.nwlondonicb.nhs.uk/cspc)

It can also be downloaded, and a paper copy of the questionnaire completed. We have set up a FREEPOST address for postal response. The address is **FREEPOST HEALTHIER NORTH WEST LONDON** (no stamp needed).

#### **By Post or email**

People can also give feedback without using our questionnaire. They can send in their contributions in a letter or an email. We ask people responding on behalf of an organisation to state the name of their organisation in the correspondence.

Contact details for postal responses are - FREEPOST HEALTHIER NORTH WESTLONDON (no stamp needed) or email: [nhsnw1.endoflife@nhs.net](mailto:nhsnw1.endoflife@nhs.net)

**By inviting members of the programme team to speak to a group or organisation**

The consultation team can be contacted by email at [nhsnw1.endoflife@nhs.net](mailto:nhsnw1.endoflife@nhs.net)

**By attending one of the consultation public meetings**

We are holding public meetings both face to face and online. These meetings are an opportunity for interested service users and residents to find out more about the consultation proposals, ask questions and to give their views. These discussions are designed to give everyone the opportunity to participate.

Full details of all events and engagement activities will be available on [the ICB website](#).

Interpreters can be booked on request for these public meetings by contacting [nhsnw1.endoflife@nhs.net](mailto:nhsnw1.endoflife@nhs.net)

A draft timetable of consultation events and planned activity is attached with this paper.