

Meeting: North West London Joint Health Overview and Scrutiny Committee

Date of meeting: Tuesday 22 October, 2024

Subject: Communications and engagement strategy for the public consultation on the new North West London model of care for adult (18+) community-based specialist palliative care services

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Section 1 – Summary and recommendations

Summary

As previously reported to the Committee, since late 2021, we have worked closely with local residents, families, carers, clinicians and charitable and NHS palliative care providers to develop a new model of care for adult community-based specialist palliative care services in North West London. Having engaged with our key audiences extensively on the model and completed the London Clinical Senate and NHSE assurance processes, we are now preparing to proceed to public consultation on the options for delivery of the model.

Recommendation:

Members are requested to review our communications and engagement strategy for the proposed public consultation

Section 2 - Main paper

2.1 Introduction

We began our work to review adult community-based specialist palliative care services in late 2021. Since then we have met and worked with patients, families and carers as well as our colleagues from charitable and NHS care providers to help us create a new model of care to improve the services and support available to all residents in north west London.

We know that people care deeply about their local services, whether charitable hospice or NHS, and how they support local residents, families and carers at what is the most difficult of times.

We also know that we need to improve services and make them better for patients and families so that they receive the care and support they need in an environment that supports and helps them at the end-of-life.

People have told us they want their care when dying not in a hospital in-patient ward environment but preferably at home, or in a more therapeutic and calm environment where they will receive the holistic care and support they, their families and their carers need. We heard repeatedly through our engagement how choice was so important, that everyone had different needs and that one size did not fit all. The importance of personalised care was also highlighted.

2.2 Why change is needed

We began this review with the publication of an issues paper in late 2021 that set out eight broad reasons we needed to improve these services, including:

- Our aging (and growing) population
- Reducing health inequalities and social exclusion
- Making services easier to access including for our more diverse communities
- Financial and recruitment challenges.

From late 2021 we repeatedly and consistently sought the views of local residents, clinicians and charitable and NHS palliative care providers on what was important to them about adult community-based specialist palliative care services. Key themes which arose throughout included:

- Providing the best possible care in the best location for the patient
- Providing personalised care reflecting individual needs
- Improving service integration and making navigating services easier
- Clear information and advice on accessing services and support
- The need for staff to be compassionate and culturally sensitive
- Better support for patients, carers and families through end-of-life and beyond, including improving access to bereavement support.

Also, very importantly, as we started to look at existing service provision in-depth, we found that there was significant variation in the type and level of care people received in different boroughs:

- In Hammersmith & Fulham, Ealing and Hounslow there was no hospice at home provision
- Patients in Harrow could not be treated for lymphoedema which was not caused by cancer
- Only patients in Hillingdon were able to get access to enhanced end-of-life care beds
- Patients in Harrow could only access specialist palliative care team services 5-days a week compared to the 7-days per week found in the other seven boroughs in north west London
- Consultant and nurse-led outpatient clinics are not available in Ealing or Hounslow
- 24/7 telephone advice has varying degrees of consultant supervision and is delivered by nurses of varying specialism
- Variation in the level of trained specialist psychology and bereavement practitioners.

As we moved forward we were careful to respond to each of these issues and to propose a model of care for north west London in which everyone receives the same level of high quality care regardless of their circumstances and where they live.

2.3 Developing the new model of care

We recognised from the very start of the programme to improve community-based specialist palliative care for adults in NW London that the only way we were going to succeed was if we worked closely with local residents, families and carers to develop services that truly meet their needs.

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.

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.

2.4 The new model of care

We have listened and worked with communities to develop a model of care that responds to identified needs while reflecting good practice and best practice evidence. Our new model of care was tested with the public in 2023 and received strong local support.

The model of care recommends the common provision of adult community-based specialist palliative care services in all eight boroughs across north west London and broadly covers three areas:

1. Care at home (adult community specialist palliative care nursing teams, hospice at home and 24/7 specialist telephone advice)
2. Community specialist inpatient beds (hospice inpatient beds, enhanced end-of-life care (EoLC) beds)
3. Hospice outpatients (including lymphoedema, psychological and bereavement services), hospice day care and wellbeing services.

Figure 2 –Model of care for community based specialist palliative care

What changes will you see in how care is provided	
Care in your own home	
Service	Key change
Adult community specialist palliative care team	7 day service available 12 hours per day in all boroughs
Hospice at home	Care available in all boroughs 7 day service, available up to 24hrs
24.7 specialist phone advice	Consultant-led advice, available to anyone
Care in a community inpatient setting	
Service	Key change
Enhanced end-of-life care beds	Increase beds from 8 beds in Hillingdon to 54 across all our boroughs
Specialist hospice inpatient unit beds	57 beds are needed to meet future need. Improve access to them by increasing hours by which people can be admitted
Outpatient and wellbeing care	
Service	Key change
Hospice MDT outpatient clinics	Increasing specialist clinics in Ealing and Hounslow to improve consistency
Dedicated bereavement and physiological support	A consistent care pathway in all boroughs offering one-to-one counselling and group settings
Lymphoedema	Expansion of service to care for cancer and non-cancer patients

In parallel to agreeing that the elements above are key to better supporting our residents to live their best possible life as well as have the most comfortable death, we acknowledge an issue for some residents in our inner London boroughs, is that the Pembridge Palliative Care Inpatient Unit at St Charles Centre for Health and Wellbeing in North Kensington has been closed since 2018, due to challenges staffing the unit. This review is focused on the right support across all eight boroughs but will also need to provide an agreed approach to the future of the Pembridge Palliative Care Inpatient Unit.

An innovative development that directly responds to resident concerns, is the proposed introduction of enhanced end-of-life care beds in all eight boroughs in north west London that will serve patients with a moderate level of need.

Enhanced end-of-life care beds will be paid for by the NHS and supported by their local specialist palliative care team providing in-reach support and expertise.

Benefits include:

- More beds closer to where people live making it easier for family and friends to visit
- Fewer people admitted to hospital at the end-of-life
- Keeping the highly specialist hospice beds for the patients with the most complex needs
- Meeting people's preferences of preferred place of death
- Improving comfort and wellbeing at the end-of-life.

There are currently eight enhanced end-of-life-care beds in Hillingdon. Based on this number and the population of each borough we are proposing the introduction of 46 additional end-of-life care beds meaning 54 in total.

2.5 Consulting on options to deliver the new model of care

Implementing the new model of care requires us to introduce new services, change existing services and make some difficult choices. We have undertaken an extensive appraisal process to explore the possible ways to deliver these changes.

An initial longlist of 54 possible options for delivery of all elements of the new model of care were assessed against key criteria determined by our [steering group](#). This resulted in a shortlist of five possible options, which will be detailed in the main consultation document.

Further financial and non-financial appraisal of these five options has resulted in two preferred options, which scored highest in the appraisal process. We will be formally consulting on these two options.

We are pleased that in these two options, we are proposing to almost double the number of beds available to local residents and fill the gaps in service provision that has meant that some residents in some boroughs have a less equal service. We believe this is the fair and right thing to do.

We are also seeking to agree the future of the Pembridge Palliative Care Inpatient Unit in North Kensington that has been suspended for over six years and before the Covid-19 pandemic, as we have been unable to recruit the necessary specialist palliative care consultant and wider team. There is a national shortage of these highly specialist staff and despite repeated attempts to recruit we have been unable to do so. We have also worked with our partners to see if there was any way round this and have been unable to find a solution. We are sorry for this and know how upset local residents continue to be.

Whilst one of the two preferred options scored higher in the financial and non-financial appraisal, no decision has been made and we will be seeking views on both options to inform the final decision. This will be made after the consultation has closed and the feedback independently reviewed.

We acknowledge that some people would have liked us to go further and be even more ambitious. Informed by our providers and clinicians we have tried to strike the right balance between what is realistic and deliverable as well as impactful. We believe the proposals strike that right balance.

2.6 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 north west London adult community-based specialist palliative care website.

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 a full public consultation has taken place and all of the information, including the feedback from the consultation, has been considered.

3. Communications and engagement strategy

The full communications and engagement strategy for the public consultation is attached with this paper.

In summary:

- The strategy is designed 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. It aims to 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. The strategy is also designed to comply with the relevant statutory duties and guidance.
- 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 and the core consultation information including: the main consultation document; a summary version; an easy read version; detailed background documents, including the Equalities Health Impact Assessment; the updated model of care; video updates and a white board animation that explores the patient journey.
- We will also provide support for those who may need 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.

- Of the nine protected characteristics identified within the Equality Act, our equality health impact assessment indicates that 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 (gender reassignment, marriage or civil partnership, pregnancy and maternity, race, sex, sexual orientation).
- Our 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. Our assessment indicates that 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.
- Following the equality health impact assessment, integrated impact assessment and a review by the Clinical Senate, the following groups have been identified as the high priorities for the consultation: residents of NW London; those populations who are under-represented in access to adult community-based specialist palliative care services (including BAME residents and younger people); and people in those wards with most limited geographical access to services and longer travel times.
- In addition, other groups we are prioritising 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.
- The consultation questionnaire and schedule of engagement activities will be publicised through a variety of channels including existing contact lists; NHS NW London and partner social media channels, websites, newsletters and mailings; our stakeholders and partners' networks; NW London and borough end-of-life groups and contacts; community organisations, local authority channels and our borough contacts; and through advertising through social media and meta channels.
- The questionnaire will be 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). Printed copies of the questionnaire, will also be made available. People will also be able to share their views with the team via email and freepost and arrange a call to feedback verbally.

- All feedback received through all the channels set out will be considered in a single analysis. 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 report will be published, form an appendix to the decision-making business case (DMBC), and be formally considered by the ICB.
- There will be 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. There will also be a number of NW London-wide events. Each event will include information on the proposals and provide opportunities to question and challenge. All comments will be considered within the consultation analysis. There will also be a programme of drop-in sessions at various locations across all eight boroughs with consultation documents available and support to consider and complete the questionnaire. A draft timetable for these events is provided with the communications and engagement strategy that accompanies this paper.
- 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.
- We will also work with the ICB Borough teams to develop an approach which identifies and seeks invitations to attend existing meetings, events and platforms.
- We will revisit the contacts we made during the development of the model of care, update them on the proposed changes and seek their views. We will also aim to reach out to the priority groups identified in the Equality Health Impact Assessment and seek in-depth conversations and interviews (where appropriate).
- The consultation is expected to begin during the week commencing 18 November 2024 and is scheduled to run for a minimum of 14 weeks (allowing two weeks for the Christmas and New Year period). The team will undertake regular review of comments and responses throughout this period 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.

