London Clinical Senate Review

NHS North West London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care.

London Clinical Senate Council Report

13th May 2024

Contents

1. Contact details of the key personnel coordinating the review process

Review Chair	Heather Richardson
Review Vice Chair	Marianne Leach
Chair of London Clinical Senate	Mike Gill
Head of London Clinical Senate	Emily Webster
Interim Head of London Clinical Senate	Robin Plata
Project Manager	Gillian Foreshew
Email	england.londonclinicalsenate@nhs.net
Website	London Clinical Senate | Providing independent, strategic advice and leadership (londonsenate.nhs.uk)

2. Foreword

On behalf of the London Clinical Senate, we are pleased to share the final report which reviews the NHS North West London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care.

This model and plans for its roll out have been a long time in conception. The London Clinical Senate received an initial proposal in 2019 for the development of palliative care services in this area. At the time, there was agreement by all involved that further work on the plans would be beneficial to enhance services for people dying and those caring for them or grieving their death. Such work has taken place, and the revised plans tell a strong story of wide consultation with the public, engagement with a broad range of providers who work in the area, and tangible attention to equality of provision across a large geographical area and diverse population. We commend this effort and considering this are pleased to support the proposed changes. We see, also, some evidence of innovative thinking and the potential upscale of some exciting developments in provision that reflect the changing demographic and clinical needs of people coming to the end of life. These proposals are exciting, and we encourage all living and working in north west London to continue to invest in novel responses to meet the palliative care needs of local people to ensure an equitable, timely and effective model moving forward.

Members of the London Clinical Senate have been ably supported in their work to review the business case and related materials by a range of experts, drawn in to offer different insights related to current and future needs for community- based specialist palliative care services. We are grateful to them for their time, considered opinions and commitment to this work. Similarly, members of the London Clinical Senate Patient and Public Voice Group have offered valued discernment regarding strengths and gaps in the consultation to date and we encourage the team taking this work forward in north west London to keep talking to local people, engaging them in clear and careful conversations about what is important to them, their choices, what they can expect, and how to access services that are relevant to their needs.

Finally, our thanks to the team based in NHS London who support members of the London Clinical Senate and its work. The timely and comprehensive nature of this report is testimony to their efforts.

Heather Richardson

Leach

Heather Richardson, Chair of Review

Marianne Leach, Vice Chair of Review

3. Executive summary and key recommendations

Following the review of NHS North West London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care, the London Clinical Senate commend the programme team for the quality and depth of the work undertaken, and the developments from the initial proposals reviewed by the London Clinical Senate in 2019.

The Senate Review Panel are supportive of the changes proposed and thank everyone for the comprehensive materials provided. We hope that the recommendations will enable the programme team to further strengthen and improve the proposals.

The recommendations align to several overarching suggestions, which are focused on achieving greatest positive impact through the proposed changes, namely:

- Continuing to develop the model to reflect contemporary, changing, and future needs.
- Adopting a lens of equity across the diverse populations of north west London to guide the design, roll out and enhancement of the model.
- Being innovative – moving beyond “the basics” of coordinating care to creating connectivity and collaboration across the patch. For example, through digital enablement and by aligning multiprofessional teams including primary care, allied health professionals and a wide range of stakeholders around the need of patients.
- Being confident that the rollout proposed is possible. This will involve due attention to the challenges of implementation; workforce availability and capability; access to care home beds; and a strong working interface with primary care and other services.
- Maintaining and developing public engagement to ensure people are using the right services at the right time.
- Building a range of quality measures and outcomes at population and patient /user reported levels, which are benchmarked, and reviewed across the patch. Using these to help review and continue to develop and improve the model to meet the breadth of the populations needs.

The specific recommendations, which are explained further in the main body of the report are detailed below.

Recommendations

Overview of the model

R1. Explore flexibilities to evolve into a modern palliative care model, emphasising the offer to patients with a range of diseases and conditions eg frailty, heart failure and chronic respiratory disease. The model described is predominantly a traditional community palliative care model, with its foundations in supporting people with cancer.

R2. Include further detail of information provision to patients as part of the service design.

R3. Further emphasise the support that the proposed service design will offer to carers.

Care in the home

R4. Provide greater clarity on the role of the call centre, both who it is designed for (staff, carers, patients) and what it offers (bed management, medication, service navigation). Outline clear principles to reduce potential hand offs.

R5. Consider the demand for the call centre and undertake modelling to help ensure that the service does not become overwhelmed; this may be achieved through a pilot in the first instance, as well as lessons learned from existing call centres/ pilots.

R6. Keep pursuing a single point of access for the call centre to enable greater equity, which may be possible with a tighter clarity on the purpose.

R7. Describe how the 24/7 planned phone service will be supported by out of hours pharmacy provision.

Care in a community inpatient setting

R8. Provide more detail when describing how the learning from innovations underway (Hillingdon Enhanced end of life care beds) will inform the plans and help implementation.

R9. Describe the governance for the Enhanced end of life care beds including model, role and responsibilities for GPs and Primary Care and how clinical issues will be communicated between different clinicians and stakeholders.

R10. Provide assurance that the assumptions made of primary care and associated responsibilities for GPs are realistic and transferrable across the whole of the Integrated Care System (ICS).

R11. Describe the support, training, and resources available to Primary Care to enable them to fulfil their extended role in relation to Enhanced end of life care beds.

R12. Provide further assurance that there is capacity within the care home sector to deliver care via an additional 50 beds as per the current Harlington Hospice model in Hillingdon including consideration of potential unintended consequences eg reduced number of beds available to other frail elders requiring such care.

R13. Describe how the workforce skills and capacity are being developed to make the aspiration of the advice and rehabilitation model of care provided by Harlington Hospice a reality.

Outpatient Care and Wellbeing

R14. Fully consider the need for specialist social care support within the specialist palliative care team following NICE recommendation 1.9 (*NG142- End of life care for adults: service delivery).*

R15. Provide more information on the proposed different services available across the patch provided by the hospices that meets complex/multiple needs including pain intervention clinics, specialist psychosocial and mental health support, breathlessness, and rehabilitation services. Confirm what is available via outpatient clinics/services. Consider patient pathway examples/ vignettes to illustrate this.

Outcomes

R16. Provide additional indicators of clinical quality and other outcomes to establish a baseline of quality of care. Consider measures that indicate improvement in effectiveness of care and identify areas for sustained quality improvement.

R17. Monitor the intended rollout and implementation to redress current inequities across the geographical patch.

Demographics and equity across the diverse populations of north west London

R18. When the Integrated Impact Assessment is complete, explore opportunities to better meet population needs and consider distribution of resources for more vulnerable populations that require support.

R19. Consider broader accessibility and inequalities eg enabling people with learning disability, stroke, and other conditions to make informed choices.

R20. Include input by different cultural and faith communities to strengthen the proposals.

R21. Consider the model of care to ensure the needs of people of all ages are met, whilst recognising the Care Quality Commission registration requirements for different types of provision.

R22. Further describe how opportunities will be maximised to strengthen the concept of compassionate communities, engage community groups, their leaders, and the broader voluntary sector to bring together community action and professional services; this is critical to ensure connection with all communities including those with protected characteristics.

Contemporary, changing, and future needs

R23. Emphasise in the narrative how the proposals may give a better opportunity for future proofing with greater flexibility and increased resilience, including reference to the environment.

R24. Provide further detail on how a stronger place-based component will be promoted to enable a more sustainable service.

Digital, data and innovation

R25. Strongly pursue the availability of the London Care Record as well as EMIS (GP systems) across all services in the pathway to facilitate best decision making and patient care.

R26. During implementation, seeking involvement in potential innovations is strongly encouraged. The transformation provides an opportunity to enhance joined up working and explore further improvement changes in partnership with service users and providers.

Patient, carer, and public engagement

R27. Describe with greater clarity how the model differs from what currently exists, where people would receive their services and how these would connect to the wider system. This may be presented in the form of a patient journey and patient vignettes.

Workforce

R28. Further describe the workforce model that underpins the plans and how the plans address existing workforce challenges.

R29. Consider increasing the workforce ambition and including plans to develop leadership and commissioning opportunities. For example, influencing organisational development; promoting staff training and upskilling; ensure recruitment processes select staff with key competencies required in the new model.

R30. Describe how the proposed introduction of the funded Macmillan post will be built upon to provide a more substantial resource/ fully established team over a longer time to help lead implementation.

R31. Consider staffing in the context of anchor institutions, describing how partners will be encouraged and/or incentivised to recruit staff that reflect the local population.

R32. Consider how identifying time for training can improve workforce skills and retention. This could be a tool for improving retention and as part of the mitigation for the workforce risk (PCBC 10.3 table 54).

R33. Include further detail on the engagement eg Local Medical Committees (LMCs) and other key bodies.

Implementation

R34. Ensure proposed leadership and organisational development are aligned to coordinate implementation and that there is integration with non-specialist systems to provide a safety net for patients.

R35. As the plans are implemented, engage, and co-produce the relevant care models with the multiple communities to increase equity.

R36. Extend engagement of the voluntary sector beyond the local hospices.

4. Background

The North West London community specialist palliative care programme has been designed to develop and implement a future north west London model of care, working closely with residents, partners, and providers. The programme seeks to better join up health and care support for residents. It focuses on the building blocks that underpin service delivery: partnerships, pathways, digital and data, and estates[1].

Adult community-based specialist palliative care (CSPC) services are part of a larger group of services that support people at the end of life. They are designed for people who have complex, and specialist needs that cannot be met by general services such as general practice and community nursing alone. They assist people away from a hospital setting to have comfortable end of life with a network of services staffed by teams with skills and training in specialist palliative care. CSPC services do not include generalist palliative care or acute specialist palliative care services, but both work closely with CSPC provision to support best outcomes for patients[2].

A key driver to the programme was that Pembridge palliative care services inpatient unit was deemed unsafe due to poor staffing levels. As a result, care provision was suspended October 2018 and inpatient bed capacity was spot purchased from other providers in north west London[3].

Subsequently, several key national and local developments have taken place:

- In 2019, the NHS Long Term Plan committed to improving personalised palliative and end of life care for people of all ages and to address health inequity[4].
- In 2022, Integrated Care Boards (ICBs) received statutory guidance on palliative and end of life care underscoring the Health and Social Care Act 2022 requirement that ICBs have a legal responsibility to commission health services that meet their population needs[5].

Since 2021, North West London Integrated Care Board has been working with its population to examine the opportunities to improve CSPC for the benefit of patients, families and carers for adults. This resulted in the publication of an Issues Paper *Community -based specialist palliative care improvement programme* (2021) detailing the ambition for everyone in north west London to receive the same high level quality care regardless of their circumstances[6].

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[1] NWL Terms of Reference, page 4, paragraph 1
[2] PCBC Executive summary, What is CSPC, page 8
[3] NWL Terms of Reference, page 6, paragraph 1
[4] NWL Terms of Reference, The National Context, page 3
[5] NWL Terms of Reference, The National Context, page 3
[6] NWL Terms of Reference, page 6&7

5. Approach to the review

The review was undertaken by the London Clinical Senate via Microsoft Teams on 5 March 2024, chaired by Heather Richardson, Director of Academic Learning and Action, St Christopher's Hospice with Marianne Leach, Consultant Paediatrician, St Georges University Hospital as vice-chair.

The Terms of Reference (Appendix G) for the review were agreed by representatives from both the London Clinical Senate and leaders from the North West London adult (18+) community-based specialist palliative care services improvement programme team (North West London Team).

The North West London Team requested specific advice and support from the Clinical Senate on:

1. Is the clinical case for change supported by best evidence and practice guidance?
2. Does the proposed new model of care and potential options for implementation improve the quality and outcomes for the community served?
3. Are the levels of stakeholder engagement and the processes for the engagement conversations held so far sufficient to support formal consultation process?

To ensure a complete and independent panel, representatives for the panel were invited from the London Clinical Senate Council and additional subject matter expertise was secured to complement and extend the panel membership.

All members were asked to sign a confidentiality agreement and to register their interests. Members considered conflicted did not contribute to the review. Whilst most Senate Review Panel members were able to attend on the day, some were unavailable due to unforeseen or unavoidable circumstances. Provision was made for these Senate Review Panel members to contribute electronically (Appendix D).

Upon receipt of the draft pre-consultation business case as well as other supporting documentation from the North West London Team (Appendix C), draft Key Lines of

Enquiry (KLOE) were produced by the London Clinical Senate (Appendix A). These were developed with reference to the *London Clinical Senate principles* and the *NHS 5 key tests for change.*

The KLOEs were discussed in a Senate Review Panel pre meet on 27 February, with subject matter experts commenting and enriching them to ensure a rounded exploration. They were then shared with the North West London Team, which in turn informed the content of their presentation on the day of the Panel.

The review was held on 5 March 2024 (Appendix B). The format was a presentation from the North West London Team (Appendix E) followed by questions from the Senate Review Panel. The review concluded with an opportunity for the Senate Review Panel to meet independently and draw together their conclusions.

To support North West London Team's desired timeline for consultation, an initial and informal discussion of the draft recommendations was provided on 15 March 2024 with an initial draft working document provided on 4 April 2024 for matters of accuracy checks.

6. Findings of the Senate Review Panel

The findings of the Senate Review Panel are aligned with the three key questions asked by North West London Team. An indication of the evidence considered, and the discussion of Panel is provided before the recommendation is made.

6.1 Is the clinical case for change supported by best evidence and practice guidance?

6.1.1 The proposals for Specialist Palliative Care in NWL have emerged from disparity of service provision and workforce challenges:

- 8 providers with mixture of charitable and NHS funding.
- Different historical commissioning arrangements leading to variable services.
- An inpatient unit being suspended for 5+ years due to staffing challenges.
- Some boroughs with multiple providers facing multiple acute sites.
- Some significant workforce challenges- as nationally.
- Different financial models.[7]

6.1.2 Against this backdrop, the North West London Team set out the reasons they were aiming to improve and increase the level of community-based specialist palliative care for adults (18+ years) in an Issues Paper *Community -based specialist palliative care improvement programme* (2021). This highlighted Specialist Palliative Care as the most fragile part of the palliative and end of life care services in NWL.

6.1.3 The case for change was evolved and refined in the pre-consultation business case[8] shared with the London Clinical Senate. This stated:

> "We identified 8 key issues that needed to be addressed:
>
> We must respond to growing levels of need and changing population preferences.
>
> We need to address inequality of provision between our boroughs - making sure that everyone receives the same level of care, regardless of where they live.
>
> We need to reduce health inequalities.
> We need to make care more joined up and easier to navigate.
>
> We must respond to feedback and engagement and build on previous work.

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[7] See- London Clinical Senate presentation pack for 5.3.24 Final. Slide 2
[8] Draft pre-consultation business case 29.1.24 (section2, pages 15-19)

> We must make sure our services are aligned to nationally recommended standards and evidence.
>
> We must ensure that our services are financially sustainable, both now and in future.
>
> We must be able to recruit and retain a suitably skilled workforce, both now and in the future.”

6.1.4 The Senate Review Panel agreed that these were important principles which future service provision should meet. They also welcomed the vision: “To have more accessible community-based specialist palliative care provision that has a wider reach for our north west London population, with the expectation that this will contribute to a reduction in hospital admissions at end of life and improve integration of care”[9].

6.1.5 The model of care emerging from the case for change seeks to combine national recommendations with local need. It was driven by a model of care working group, which was established in 2022 with half of the members being people who had either experienced bereavement or were providing care to people at the end of life. The other participants included clinicians and current providers of community specialist palliative care (CSPC) services in North West London Integrated Care System (ICS). The group drew on a range of key national policy documents, guidelines, specifications, reports, and resources to iteratively co-design the model of care with communities and service providers.

6.1.6 The Panel commended the approach, observing that there had been significant progress in thinking and planning across a broader space following the suspension of Pembridge inpatient unit, which had predominantly affected patient care in three boroughs in the north of the ICS.

6.1.7 The model of care has been built on firm foundations with the following principles or assumptions underpinning its development[10]:

- **“Demand modelling** over a 10 year period – we believe this planned model for bedded capacity will deliver over a 5 year period and we will need to plan beyond that whilst implementing

- Model of care is **the ‘what’ and not the ‘how’ deliver** – this important as each borough has different set up of integrated delivery of care with community health, primary care, social care.

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[9] Draft pre -consultation business case.29.1.24. Section 4.1 p26

[10] See- London Clinical Senate presentation pack for 5.3.24 Final. Slide 7

- **Good engagement** with local partners – eg social care – boroughs to work through how to deliver.

- **Care homes**- We have sufficient beds – but not always the ‘right kind’ – and variable in engagement.

- Getting the **basics right** – we have sought to marry up ambition with deliverability. Acute view – would want to see single point of access – but not yet identified an operationalisable [sic] model.

- **Interdependencies** – where there are a) interface issues or b) improvements highlighted for universal services we have drawn these out. There is no widespread change to universal services needed to deliver this model.

- **Spot purchasing** - planned capacity means can meet in sector needs.

    - Retain our current ability to spot purchase outside NWL (assuming not utilising capacity already funded by another ICB). However minimal outside NWL flow. Non-palliative care spot budget available to reflect patient choice.

- **Neighbouring ICBs**

    - Disaggregated commissioning for Royal Trinity Hospice reflecting different approaches and model shared.

    - Good communication flow with NCL – eg re Marie Curie changes

- **Resilience.** Hospices working as a collaborative enables support and cover – several good examples of this.”

6.1.8 These principles for improvement were recognised as providing a strong case for change, although the Panel considered that some of them were met more robustly than others. They therefore recommended furthering the level of ambition in some areas to provide a stronger and more sustainable model.

6.1.9 The resultant proposed changes to CSPC services fall into three categories:

- Care in the home.
- Care in a community inpatient setting.
- Outpatient care and wellbeing.

6.1.10 The proposed community-based model was considered effective in improving the service enabling it to adapt swiftly to meet growing, changing and emerging needs in the local communities.

6.1.11 The Panel judged that the proposed new model was informed by a solid understanding of the evidence base, and that key NICE guidelines *End of life care for adults* (NG142) and *Care of dying adults in the last days of life* (NG31)[11] were being addressed within the proposals. There was also a clear intent to make improvements where the current service provision does not meet NICE recommendations equitably across the ICS footprint. The detail of where the proposals could be strengthened to meet the guidelines more comprehensively are included in the relevant sections of this report.

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[11] See: https://www.nice.org.uk/guidance/ng31 This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

6.2 Does the proposed new model of care and potential options for implementation improve the quality and outcomes for the community served?

6.2.1 Overview of the Model

The three main areas of service and proposed changes in the Model of Care are detailed in the table below[12]:

Service	Key Change
A) Care in the home	
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 24 hrs.
24/7 specialist phone advice	Consultant-led advice, available to anyone.
B) Care in a community inpatient setting	
Enhanced end of life care beds	Increase beds from 8 beds in Hillingdon to 54 beds across all our boroughs.
Specialist hospice beds	57 beds across existing operational sites. Improve access to them by increasing hours in which people can be admitted. Closure of Pembridge as a hospice inpatient unit.
C) Outpatient & Wellbeing Care	
Hospice MDT outpatient clinics	Increasing specialist clinics in Ealing & Hounslow to improve consistency.
Dedicated bereavement & Psychological support	A consistent care pathway in all boroughs offering one-to-one counselling & group sessions.
Lymphoedema	Expansion of service to care for cancer and non-cancer patients.

6.2.1.1 The proposed model promotes collaboration between universal services and hospices; the North West London Team advised that this ethos of joint working was established during the pandemic. The Panel recognised that the whole system offer and

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[12] See- London Clinical Senate presentation pack for 5.3.24 Final. Slide 10

intention to equalise service provision across the ICS had the potential to improve the quality and outcomes for the community served.

6.2.1.2 They also reflected that services should be needs-based and sufficiently flexible to evolve to a modern delivery of palliative care, which recognises the many different trajectories of dying. The proposed model seeks to secure the fundamentals. NWL acknowledge it is not the most innovative model; it will therefore be important to iterate the model according to emerging evidence. There is potential to build on the proposals by drawing out the support for generalist services to improve the overall care provision, enabling non-specialists to develop competence and confidence in other areas of the services.

R1. Explore flexibilities to evolve into a modern palliative care model, emphasising the offer to patients with a range of diseases and conditions eg frailty, heart failure and chronic respiratory disease. The model described is predominantly a traditional community palliative care model, with its foundations in supporting people with cancer.

6.2.1.3 In line with NICE guidance (NG142- *Providing information recommendation 1.4)* there is provision within the proposed model for people to receive different levels of support and intervention during their illness as their needs change. This is critical given that evidence shows that lack of knowledge about end of life care services and poor communication with health and social care practitioners, are barriers to people understanding their treatment options and confidently making decisions about care.

6.2.1.4 There is opportunity to strengthen the model by building in plans to provide information to patients as part of the service design to support shared decision making and enhance experiences of care. This could be informed by the work in Hillingdon led by Harlington Hospice, particularly the use of digital innovation to enhance information and provide guidance to local people about what is available to them and when.

R2. Include further detail of information provision to patients as part of the service design.

6.2.1.5 Further attention may also be given to how the service design supports the needs of carers in line with NG150 *Supporting adult carers* (particularly 1.9.1-1.9.15 supporting carers when the cared for is at end of life and QS13 and QS5): “1.3.1 Local authorities, and social care organisations delegated by local authorities to carry out carers' assessments, should make arrangements for and carry out assessments in cooperation with other relevant health and social care organisations (in accordance with the Care Act 2014 and associated Care and support statutory guidance and the Children and Families Act 2014).”

R3. Further emphasise the support that the proposed service design will offer to carers.

6.2.2 Care in the home

6.2.2.1 The suggested model improves availability of service provision through the availability of an adult community specialist palliative care team in all boroughs 7 days a week 12 hours per day, and hospice at home 7 days a week for up to 24 hours. This was deemed a positive development.

6.2.2.2 It also proposes a 24/7 telephone service. This goes part way to meeting NICE recommendations and related quality standards on planning out-of-hours care (NG142 recommendation, 1.12, and QS13, statement 4), with recommendations for pharmacy provision still requiring attention.

6.2.2.3 The Panel felt that developing a single point of access for the service would be important; this is in line with the feedback the NWL Team received from acute colleagues. Whilst recognising the challenges of achieving this given a range of IT systems and different services providing telephone advice for community teams across the patch, the Panel recommend further work to ensure consistency in the operating models and to reduce the potential of inequity across north west London.

6.2.2.4 The Panel reflected that different stakeholders using the advice line would have varying needs and that clinicians taking calls must have access to appropriate information to be able to support and sign post effectively. Access to GP systems and London Care Record or Universal Care Plan are likely to be important. The model was explored with the North West London Team, and issues such as workforce and complementary work taking place with Non-Emergency Patient Transport Services contract were discussed.

6.2.2.5 The Panel were encouraged by the attempt for consistency, whilst proposing areas to further strengthen the proposal.

R4. Provide greater clarity on the role of the call centre, both who it is designed for (staff, carers, patients) and what it offers (beds management, medication, service navigation). Outline clear principles to reduce potential hand offs.

R5. Consider the demand for the call centre and undertake modelling to help ensure that the service does not become overwhelmed; this may be achieved through a pilot in the first instance as well as lessons learned from existing call centres/ pilots.

R6. Keep pursuing a single point of access for the call centre to enable greater equity, which may be possible with a tighter clarity on the purpose.

R7. Describe how the 24/7 planned phone service will be supported by out of hours pharmacy provision.

6.2.3 Care in a community inpatient setting

6.2.3.1 The two key components of community inpatient care in the proposed model are:

- Enhanced end of life care beds - which increase from 8 beds in Hillingdon to 54 beds across all boroughs.
- Specialist hospice inpatient unit beds- 57 beds intended to meet future need and with access increased by increasing hours in which people can be admitted.

6.2.3.2 The increase in Enhanced end of life care beds is a positive model and builds on the experience of the Harlington Hospice in Hillingdon; there are assumptions that the same model of care, advice and rehabilitation provided by Harlington Hospice will be available for all.

6.2.3.3 The proposals would benefit from describing in further detail the aspects of the Harlington Hospice service that they would like to extend. This includes further information and evaluation on how the Enhanced end of life care beds and other innovations might support actions elsewhere in the ICB eg upskilling GPs and Health Care Assistants. Further consideration or evidencing of the operational detail to ensure that this approach can be scaled across the wider ICB will be important to provide confidence in implementation.

6.2.3.4 The Panel noted that the community Enhanced end of life care beds place the GP as the responsible practitioner for growing numbers of people who can expect end of life care in care homes and for those who wish to remain at home. The NWL Team advised they had received feedback from GPs who felt that this should upskill and empower them, that it should support the relationship between GPs with patients and their families, leading to greater satisfaction as well as a reduced workload. It will be important to ensure that there is the capacity and skill to achieve this; further discussion and engagement will be required.

R8. Provide more detail when describing how the learning from innovations underway (Hillingdon Enhanced care beds) will inform the plans and help implementation.

R9. Describe the governance for the enhanced beds including model, role and responsibilities for GPs and Primary Care and how clinical issues will be communicated between different clinicians and stakeholders. (15- plus feedback from post review meeting)

R10. Provide assurance that the assumptions made of primary care and associated responsibilities for GPs are realistic and transferrable across the whole of the Integrated Care System (ICS).

R11. Describe the support, training, and resources available to Primary Care to enable them to fulfil their extended role in relation to Enhanced end of life care beds.

R12. Provide further assurance that there is capacity within the care home sector to deliver care via an additional 50 beds as per the current Harlington Hospice model in Hillingdon including consideration of potential unintended consequences eg reduced number of beds available to other frail elders requiring such care).

R13. Describe how the workforce skills and capacity are being developed to make the aspiration of the advice and rehabilitation model of care provided by Harlington Hospice a reality.

6.2.3.5 North West London ICB currently commissions 67 hospice beds, of which 57 are operational. Historically, 13 beds at Pembridge inpatient unit in the north of the ICB were suspended in October 2018. The equivalent of 3 spot purchase beds are now used. The demand and capacity calculations which assume an 85% occupancy conclude that this would provide a sufficient bed base for the immediate future but that after 2027/28 they would expect to adjust demand or capacity.

- 57 beds equates to an average of 2.73 estimated hospice inpatient beds per 100,000 population with a range of 2.29 to 3.28.
- 67 beds equates to an average of 3.21 estimated hospice inpatient beds per 100,000 population with a range of 2.29 to 4.05 with a higher than average bed provision in the tri-borough areas where Pembridge inpatient unit is located[13].

Given the lack of national benchmarking to help determine the recommended number of inpatient beds for the ICS, the Panel felt that the capacity assumptions were reasonable, particularly in consideration of the equity of service provision and value for money. No concerns were raised regarding the balance of the overall total of inpatient beds to Enhanced end of life care beds.

6.2.4 Outpatient care and wellbeing

6.2.4.1 The two key components of outpatient care and wellbeing are described as:

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[13] Draft pre -consultation business case.29.1.24. Section 4.4 p29-30

- Hospice MDT outpatient clinics - Increasing specialist clinics in Ealing and Hounslow to improve consistency.

- Dedicated Bereavement & Psychological support - A consistent care pathway in all boroughs offering one-to-one counselling and group sessions.

6.2.4.2 The drive for increasing equity was welcomed by the Senate Review Panel. They explored the concept of the hospice MDT outpatient clinics with reference to the NICE guidance (especially NG142- *End of life care for adults: service delivery recommendation* 1.9). The description of the service offer in the pre-consultation business case is quite narrow; following discussion it was considered that the breadth and depth of the team may not be fully demonstrated in the written documentation.

6.2.4.3 The Panel considered that there should be a needs-based approach to the suite of services offered by health and social care professionals from the hospice and more widely, which recognises the expertise and high skill level required.

> **R14. Fully consider the need for specialist social care support within the specialist palliative care team following NICE recommendation 1.9 (NG142- *End of life care for adults: service delivery*).**
>
> **R15. Provide more information on the proposed different services available across the patch provided by the hospices that meets complex/multiple needs including pain intervention clinics, specialist psychosocial and mental health support, breathlessness, and rehabilitation services. Confirm what is available via outpatient clinics/services. Consider patient pathway examples/ vignettes to illustrate this.**

6.2.5 Outcomes

6.2.5.1 There is a clear driver for improvement expressed in the pre-consultation business case with proposed overarching benefits cited as improved quality of care for people at the end of life and improved value for money. Figure 13 in the PCBC details 4 intended outcomes:

- Improved patient and carer experience.
- Care is aligned to individual needs (improved personalisation).
- Inequalities of CSPC provision are addressed.

- More people die in preferred place of death. Fewer people die in hospital[14].

6.2.5.2 The Panel considered that there are opportunities to better refine outcomes, and to identify specific measures to be captured. They recommend building a range of quality measures and outcomes (at population and patient /user reported levels, benchmarked, and reviewed across the patch) to help develop and improve the model to meet the breadth of needs across the diverse populations of north west London. A baseline assessment of key population and quality indicators across the patch could help elucidate areas of inequity which need prioritisation in the roll out of the model.

6.2.5.3 The Panel reflected on the limitations of preferred place of death as an outcome measure, given that people's views may change the closer they are to death and there may be valid reasons which restricts choice.

6.2.5.4 There was active discussion as to how to capture meaningful outcomes, including proposing reference to symptom burden and other patient/user related outcome measures aligned to focus on increasing quality in all the settings.

6.2.5.5 The Panel suggest that it would be helpful to consider patient related outcomes such as those available in the Outcome Assessment and Complexity Collaborative (OACC) suite of measures, attending to phase of illness, function, and symptom burden. This data can be aggregated a team, organisational, and system levels, and will augment other data regarding impact of palliative care such as admissions in final quarter of life, readmission rates, Emergency Department attendances and carer satisfaction.

6.2.5.6 Enhanced outcome measure could support benchmarking and enable continuous improvement. The Panel felt there are opportunities to take the proposed service model beyond equality of provision to providing equity of care. Further outcome data will be essential in indicating where resources might be appropriately moved to address the needs of more vulnerable populations.

R16. Provide additional indicators of clinical quality and other outcomes to establish a baseline of quality of care. Consider measures that indicate improvement in effectiveness of care and identify areas for sustained quality improvement.

R17. Monitor the intended rollout and implementation to redress current inequities across the geographical patch.

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[14] Draft pre -consultation business case.29.1.24. Section 4.12. Figure 13: Benefits mapping p39

6.2.6. Demographics and equity across the diverse populations of north west London

6.2.6.1 The model of care seeks to standardise service provision across the ICB. This improves accessibility compared to the status quo. However, the Panel heard that the concept of personalised care shone through in the feedback from the engagement process and that one size does not fit all. This will therefore require development going forwards.

6.2.6.2 It will be important to gain insights from the completed Integrated Impact Assessment to explore opportunities to better meet population needs, as well as consider distribution of resources for more vulnerable populations that may require support. This should include a full travel analysis including travel times with different modes of transport. In addition, boroughs will need to interpret the model for their local geography and population, supported by the local end of life forum and to guide the design, roll out and enhancement of the model.

6.2.6.3 Consideration will need to include a range of factors such as cultural competency as well as building and developing the range of end of life care pathways for conditions in conjunction with London networks. It will be important that there is a distinction between complexity and co-morbidity recognising that an individual may have complex care requirements with or without co morbidities.

6.2.6.4 There are also areas highlighted in NICE guidance that warrant consideration given the evidence that health inequalities are experienced by people who are homeless and who have learning disabilities.

6.2.6.5 The model provides greater opportunity to address and respond to culture and faith around death. It would be good to see this further enhanced. It will also be important to consider the potential for the proposed support for nursing beds model to fall short of meeting the needs of a numerically small younger cohort who have significant requirements.

R18. When the Integrated Impact Assessment is complete, explore opportunities to better meet population needs and consider distribution of resources for more vulnerable populations that require support.

R19. Consider broader accessibility and inequalities eg enabling people with learning disability, stroke, and other conditions to make informed choices.

R20. Include input by different cultural and faith communities to strengthen the proposals.

R21. Consider the model of care to ensure the needs of people of all ages are met, whilst recognising the Care Quality Commission registration requirements for different types of provision.

> **R22. Further describe how opportunities will be maximised to strengthen the concept of compassionate communities, engage community groups, their leaders, and the broader voluntary sector to bring together community action and professional services; this is critical to ensure connection with all communities including those with protected characteristics.**

6.2.7 Contemporary, changing and future needs

6.2.7.1 The NWL Team outlined their methodology for calculating current and future need, noting that using current activity as the sole predictor of future activity is likely to be flawed, as there may be cohorts of people who feel excluded or who chose not to access services. They recognised that basing future projections on this could risk "baking in" inaccurate assumptions.

6.2.7.2 The challenge of finding a reliable alternative was also outlined by the NWL Team eg they explored obtaining data via the Association of Palliative Medicine but due to variation in bed counting, and interplay with wider services including community services, confidence in a realistic alternative projection was not possible.

6.2.7.3 An outcome of these challenges means that the NWL Team believe they can plan for this proposed model of care providing the right capacity for approximately 5 to 7 years before they will need to iterate. The Panel heard the NWL Team's belief that the underpinning partnership ethos, relationships and established operational groups would enable them to build upon these solid foundations.

6.2.7.4 Intuitively, the Panel anticipated that a community facing model would demonstrate better environmental sustainability. They encourage the NWL Team to provide assurance that this has been fully explored, as well as considering adaptation to climate change and resilience plans for extreme weather events such as heat and flooding.

> **R23. Emphasise in the narrative how the proposals may give a better opportunity for future proofing with greater flexibility, and increased resilience including reference to the environment.**
>
> **R24. Provide further detail on how a stronger place-based component will be promoted to enable a more sustainable service.**

6.2.8 Digital, Data and Innovation

6.2.8.1 Digital, data and innovation are fundamental enablers to the service, important for governance, as well as targeting and reducing inequalities. There are many digital opportunities to support the implementation of these changes, examples being the sharing of records, patient access to their own records and communication through the 24-hour help line. Further detail on digital opportunities to enhance the plans should be explored.

6.2.8.2 The Panel considered how the NWL Team were using technology to support the interface and collaboration between teams. An end of life dashboard is currently work in progress, supported by Whole Systems Integrated Care (WSIC) with plans to roll out Universal Care Plan data into care homes and hospices to enable individual support to patients. There appears an opportunity to build on work by Harlington Hospice in Hillingdon to create a shared patient record; this will be particularly supportive for the team leading the helpline.

6.2.8.3 The Panel felt that a single shared record would be key to the successful implementation. Achieving this may require support and prioritisation from the Integrated Care Board.

> **R25. Strongly pursue the availability of the London Care Record as well as EMIS (GP systems) across all services in the pathway to facilitate best decision making and patient care.**

6.2.8.4 There is also the potential to give further attention to innovation to enhance equity. The suggested model focusses on getting the fundamentals right to achieve equality. Whilst the desire to ensure greater equality of provision across a patch that has historically experienced different service provision according to geography/postcode is welcomed, this approach denies opportunity to ensure greater equity, with particular attention to communities traditionally excluded/ living on the margins.

> **R26. During implementation involvement in potential innovations is strongly encouraged. The transformation provides an opportunity to enhance joined up working and explore further improvement changes in partnership with service users and providers.**

6.3 Are the levels of stakeholder engagement and the processes for the engagement conversations held so far sufficient to support formal consultation process?

6.3.1 Patient, Carer, and Public Engagement

6.3.1.1 Engagement with the public has taken place over several years and has been extensive. This began in 2018 with the temporary closure of Pembridge inpatient unit and has continued to iterate.

6.3.1.2 A model of care group with residents and staff across the system has met weekly a total of 38 times to discuss and refine the proposed models, enabling detailed and completed conversations with a clear feedback loop. They developed a draft model of care which was tested with residents, with feedback prompting a greater focus on personalisation. Twelve patient and carer representatives contributed to the model of care group (approx. 50% of total membership).

6.3.1.3 A stakeholder steering group was also established with representation from two patient and carer representatives, representing a good percentage of the overall membership[15].

6.3.1.4 There has also been a substantial level and range of feedback from the wider public with the engagement activities culminating in the publication of the engagement outcome report in March 2023 which fed into the development of the model of care[16].

6.3.1.5 The NWL Team considered that it would not be possible to gain a representative voice of patients and carers to attend the Senate Panel review day, given their experience of different services and a range of perspectives. Ideally the Panel would have wished to explore the degrees of engagement with patient and carer representatives on the day but recognise and respect the rationale and decision taken.

6.3.1.6 The Panel wish to highlight the need for discussion with communities about their expectation of service provision to help ensure that people use the appropriate services for their needs at the right time.

6.3.1.7 There is potential risk of a gap between the offer (access criteria) and an individual's needs and wishes, which may change over time. There is often a desire from the public to be seen by the specialists in a particular field. Throughout public consultation it will be important to convey that while most patients do not require specialised care, the plans will improve services for all people at the end of life. This recognises that fundamental to the proposals is spreading knowledge and developing clinical competency

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[15] Draft pre -consultation business case.29.1.24. Section 15. Appendix C p90
[16] Draft pre -consultation business case.29.1.24. Section 3.3 p22

across the whole system. For some people, effective coordination in primary care will better meet their needs than, for example, specialist inpatient care.

> **R27. Describe with greater clarity how the model differs from what currently exists, where people would receive their services and how these would connect to the wider system. This may be presented in the form of a patient journey and patient vignettes.**

6.3.2 Workforce

6.3.2.1 The pre-consultation business case recognises the need to address workforce[17]:

“Meeting the changing needs of our population invariably means making sure we have a workforce model that responds to increasing demand. We will work with providers to develop a detailed workforce plan. Principles for how we develop this are that by working together:

- Providers will be better placed to make recruitment decisions that better serve the needs of our communities.
- Providers can share details about roles and opportunities to support internal progression, thereby supporting retainment within NW London.
- Providers can shape and deliver education and training programmes that make NW London an attractive place for people to work.
- Providers can discuss ongoing challenges to recruitment to collectively find solutions.”

6.3.2.2 The Panel recognised these as laudable principles, whilst also identifying the importance of attending to specific aspects within this.

6.3.2.3 The new model introduces different ways of working and has significant impacts on workforce. The North West London Team recounted that they had candid conversations with providers about feasibility as well as regular weekly meetings with Directors of Adult Social Services and Directors of Public Health and Local Authority Care home leads to ensure close working across universal services.

6.3.2.4 They consider that the model could provide attractive development opportunities to staff with roles with specialisms and enhancements and believe there is workforce availability and capability based on previous recruitment.

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[17] Draft pre -consultation business case.29.1.24. Section 4.3 p30

6.3.2.5 A key observation was that primary care are fundamental to the success of the model, particularly around Enhanced end of life care beds. Therefore, support from GPs and their local leadership body is critical to this change.

6.3.2.6 The Senate Review Panel recommended several areas to strengthen the workforce proposals:

R28. Further describe the workforce model that underpins the plans and how the plans address existing workforce challenges.

R29. Consider increasing the workforce ambition and including plans to develop leadership and commissioning opportunities. For example, influencing organisational development; promoting staff training and upskilling; ensure recruitment processes select staff with key competencies required in the new model.

R30. Describe how the proposed introduction of the funded Macmillan post will be built upon to provide a more substantial resource/ fully established team over a longer time to help lead implementation.

R31. Consider staffing in the context of anchor institutions, describing how partners will be encouraged and/or incentivised to recruit staff that reflect the local population.

R32. Consider how identifying time for training can improve workforce skills and retention. This could be a tool for improving retention and as part of the mitigation for the workforce risk (PCBC 10.3 table 54).

R33. Include further detail on the engagement eg Local Medical Committees (LMCs) and other key bodies.

6.3.3 Implementation

6.3.3.1 Implementation is addressed in section 10 of the pre-consultation business case, with the hope that implementation can commence in November 2024. The core team leading on this are described in 10.2.1.

6.3.3.2 Further outlining the governance mechanisms that will help ensure cohesive system improvements across the broad provider landscape would be beneficial. Inclusion and engagement of communities and voluntary groups to support conversations and co-design of the model to reflect marginalised or excluded groups, or currently unaddressed needs would strengthen the quality of care.

R34. Ensure proposed leadership and organisational development are aligned to coordinate implementation and that there is integration with non-specialist systems to provide a safety net for patients.

R35. As the plans are implemented, engage, and co-produce the relevant care models with the multiple communities to increase equity.

R36. Extend engagement of the voluntary sector beyond the local hospices.

Appendix A- Key Lines of Enquiry (KLOE)

The Clinical Senate developed Key Lines of Enquiry with reference to the London Clinical Senate Principles

DRAFT Key Lines of Enquiry (KLOE)

For Pre Review meeting discussion and development

v0.9

NHS North West London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care

The sponsor is requesting advice and support from the Clinical Senate to provide comment / advice on:

Is the clinical case for change supported by best evidence and practice guidance?

Does the proposed new model of care and potential options for implementation improve the quality and outcomes for the community served?

Are the levels of stakeholder engagement and the processes for the engagement conversations held so far sufficient to support formal consultation process?

Is the clinical case for change supported by best evidence and practice guidance?

You state "by 2040, demand for palliative care is expected to increase by 25% to 47%". Does the proposed new model of care lend itself to demographic shifts? How will service provision be future proofed?

What would the model demand of support structure and service?

How, within the current proposal, could you enhance the community contribution to care- to reflect the sixth ambition "each community is prepared to help"?

Does the proposed new model of care and potential options for implementation improve the quality and outcomes for the community served?

How would the proposed model impact on younger adults and transition?

How do you see spot purchase arrangements impacted? Is there provision for this?

What working interface do you envisage between hospital services/secondary care and the new community model to:

Facilitate the innovations you propose e.g. rapid discharge.

Support a more integrated approach for patients moving between hospital and home/the community?

How will you monitor a balanced set of quality and outcomes – including cost effectiveness, measures of equality and equity, patient reported outcomes etc.

How are the mental health and wellbeing needs of patients and carers supported?

Are the levels of stakeholder engagement and the processes for the engagement conversations held so far sufficient to support formal consultation process?

What engagement has there been with neighbouring boroughs where there might be shared funding streams?

Are there any significant cross boundary flows to be aware of?

How have you engaged with social care, from an operational perspective?

How will the proposed model be maximised e.g. supported by conversations with the clinical team?

Subject Matter expertise

In addition to the questions posed above, we invited panel members to focus questions on areas of specialism. Initial questions, which panel members may add and refine on the day, is below:

Palliative Care – Voluntary and Community

Heather Richardson (Chair)
How do you envisage assisting patients, families, carers, and others navigate the system and confirm what is available to them?
Palliative Care- Secondary and Hospital interface *Polly Edmonds (Consultant in Palliative Medicine)* *Lucy Pain (Palliative Care Consultant)* *Maurice Cohen (Consultant geriatrician)*
What are the respective admission criteria for care home beds compared to hospice bed? What is nursing home bed availability across the area and how even is the distribution? Are there any plans to support generic nursing home beds (recognising that they are not part of this review)? How confident are you that care homes and particularly nursing homes across the patch are able and have capacity to become an integral part of the model? How will the new community-based model have flexibility in provision to meet: Elders' needs? Other diverse and broad needs within the NW patch including those intersectional in nature? A more equitable service, particularly for those currently excluded, marginalised or underrepresented in the palliative care population served? (geriatrician)
Public Health and Healthcare Inequalities *Gladys Xavier*

Given there will be different demographic needs across a large geography, to what extent does the spread of beds and community services match the need at place/ borough/ within the ICB (table 9). How might work with the voluntary and community sector best support patients' diverse needs?
Primary Care *Sumeeta Dhir* *Naureen Bhatti*
How would the new model interface with primary care and established community nurses and social care support and capacity? What plans and reassurance do you have that primary care and other community services can provide the input required 24/7 to complement the new model and support it, particularly in the 12 hours a day when specialist support is limited to telephone advice only? What criteria will be in place to enable access 12-hour care being offered?
Pharmacy *Jas Khambh*
How will pharmacy support be integrated to ensure: Timely access to medicines around the clock Opportunities to reduce overtreatment at the end of life (pharmacy)
Travel and Transport *Tim Edwards and others*
What provision has been made for timely transfer of patients to and from hospital/hospice and home to facilitate rapid discharge where hospital care is no longer required? (LAS)

Have travel calculations considered the particular needs of this population, which may be longer than average travel time?
Allied Health Professionals *Adrian Capp*
Which elements of the model allow patients living with advancing illness to maintain function and achieve their goals, consistent with a rehabilitative focus? How will you promote this approach in the new model?
Anaesthesia & Pain Medicine *Natasha Curran*
Where do you envisage provision of interventionalist pain management? What plans are there to evaluate, improve and evolve the service continually after implementation?
Workforce *Liz Carty (desktop)* *Naureen Bhatti*
Please can you talk us through your workforce strategy: The model proposes extension from 5 to 7 days a week working in some areas. Is there a workforce plan that supports this? What are your plans around workforce retention? What training do you envisage for the different groups of staff who are vital to the success of this model? e.g. Care home staff. How as an anchor organisation/provider do you plan to support local communities with your workforce proposals? Is there support / protected time in place for training and development?

Health & Care in the Community

Pauline Fahy (desktop)

What are the options around hospice at home availability. What else is being offered? Can community nursing support?

How have you considered the local context – characterised by diverse population, extraordinary mix of providers across variable locations?

Is there any intention to support community response beyond professionals? How will they protect and support families and community partnerships?

Patient and Public Voice

Khushboo Patel

Lucy Brett

What have you learnt about what the community/communities would like to do to support people to die and grieve better in the area that could be complementary to the development of professional services?

How could you maximise these?

PCBC shows positive engagement. To what extent do those providing feedback reflect the demography of the wider population?

(3.6 table 7). How has the feedback received informed the proposals to date and what further needs to be done. Is there a clear plan/ confidence that this will happen?

How do the proposals recognise the potential future aging population with a growing number of conditions who are currently less likely to experience a good enough death and appropriate support in related bereavement or loss?

How have you addressed the cultural variations in attitudes towards death?

Infection Prevention Control/ Healthcare Science

Elaine Cloutman-Green

Whole system pathway/ unintended consequences

All panel members

How will the proposals facilitate a broad group of providers coming together at ICB level to develop a new approach that “does better things” and with a transformational focus?

What leadership will you put in place to assist this?

How resilient are your plans to cope with unexpected issues e.g. the potential closure of Marie Curie Hampstead or any other unexpected events in neighbouring Integrated Care Systems.

Evidence Base -Jade Stacey from NICE desktop

Environmental sustainability and moves to carbon neutral

Have you liaised with Greener NHS leads in your ICB to consider the proposals from a carbon and environmental sustainability perspective?

How can the model reduce the overall carbon footprint?

What consideration has been given to climate adaptation and resilience?

Innovation and Digital enablers

What opportunities exist for digital enablement?

Are you able to expand on how diagnostic and support services will support this model?

What are your plans to share digital records across primary and secondary care? How can you ensure a seamless transition?

Have any opportunities to work with virtual wards been explored?

How have you considered the use of technology / innovation to provide better outcomes?

How do your plans integrate with other current work programmes like Universal Care Plan?

Appendix 1) London Clinical Senate Council Principles (For reference)

- ✓ Promoting **integrated working across health and across health and social care** and ensure a seamless patient journey
- ✓ Being **patient-centred and co-designed** (this includes patient experience, patient involvement in development and design of services)
- ✓ Reducing **inequalities** (this involves understanding and tackling inequalities in access, health outcomes and service experience, between people who share a protected characteristic and those who do not, and being responsive to the diversity within London’s population)
- ✓ Demonstrating **parity of esteem between mental and physical health** for people of all ages
- ✓ Supporting **self-care** and **health and wellbeing** Improving **standards and outcomes** (these include use of evidence and research, application of national guidance, best practice and innovation)
- ✓ Ensuring **value** (achieving the best patient and population outcomes from available resources)
- ✓ Demonstrate how **environmental sustainability and moves to carbon neutral** are included in plans and developments. This includes reference to the National ambition to reach carbon Net zero by 2040 and the London Health Board ambition to ensure that every Londoner breathes safe air.

Appendix B - Panel Day Agenda

London Clinical Senate Review:
NHS North West London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care

AGENDA

Date: Tuesday 5th March 2024 | **Time:** 09:00-13:00

	Time	Description	Papers	Lead
1.	09:00	**Convene on Teams and pre-meet** *(Clinical Senate Panel Only)*		Heather Richardson, Chair of Review Panel
2.	09:05-09:30	**Welcome and introductions** • Key task/advice requested • Conflicts of interest declaration and confidentiality agreement • Setting the scene	Terms of Reference Key Lines of Enquiry (KLOE)	Heather Richardson, Chair of Review Panel
		Presenting team join the meeting		
3.	09:30-10:00	**Presentation addressing the Key Lines of Enquiry:** Summarising the strategic context, Case for Change, purpose of the proposed reconfiguration, clinical model and engagement	Presentation to be given on the day	Jane Wheeler NHS NW London Local Care Programme Director Dr Lyndsey Wiliams NHS NW London GP clinical lead for palliative end of life care and care homes
4.	10:00-11:45	**Panel Questions and Answers in relation to Presentation** between the clinical senate Panel and the Presenting team relating to key lines of enquiry and the presentation.	All documentation including PCBC and appendices	Heather Richardson, Chair of Review Panel
5	11:45-11:55	**Presenting team leave meeting** **Panel break – 10 mins**		
6.	11:55-13:00	**Panel discussion and deliberation:** Key findings, evidence base and emerging themes for recommendations	All documentation- including PCBC and appendices	Heather Richardson, Chair of Review Panel

Appendix C- Documentation provided by North West London ICB

Papers provided to Panel

- Review Terms of Reference
- Review Key Lines of Enquiry

Document Pack

Document Reference Number	Document Title
0	Clinical Senate key documentation checklist page with links to docs 31.1.24
1a	NHS NW London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care - London Clinical Senate - Terms of Reference
1b	NW London Palliative Care proposed timeline v0.3 Clinical Senate 7.12.23
2a	Draft NW London adult community-based specialist palliative care services pre-consultation business case ***26.2.2024 NWL CSPC draft PCBC final submitted to Clinical Senate.doc (contains financial information)- available to panel on request***
3a	NW London community-based specialists palliative care Issues paper November 2021
3b	NW London community-based specialists palliative care summary issues paper November 2022
4a	North West London ICS community-based specialist palliative care for adults (18+): Co-designing a new, improved model of care January 2024

4b	North West London ICS community-based specialist palliative care for adults (18+): Co-designing a new, improved model of care August 2023
4c	North West London ICS community-based specialist palliative care for adults (18+): Co-designing a new, improved model of care summary August 2024
4d	North West London ICS community-based specialist palliative care for adults (18+): Co-designing a new, improved model of care one page infographic August 2025
5a	NW London community based Specialist Palliative Care Review Programme: Refreshed 10-year demand projections for hospice inpatient care 2023 to 2033 published January 2024
6	CQC reports for current providers of adult community-based specialist palliative care services in NW London: As of 26 January 2024
7	Schedule of evidence and best practice that have informed the proposals – No document
8a	NW London Adults (18+) community-based specialist palliative care programme Equality health impact assessment on the proposed model of care 24 November 2024
8b	NHS NW London Equality Health-inequality Impact Assessment Panel outcome for CPSC model of care review
8c	NHS North West London Adults (18+) community-based specialist palliative care programme Draft equality health impact assessment on potential options for the delivery of the model of care 11 December 2023
8d	NHS NW London Equality Health-inequality Impact Assessment Panel outcome for CPSC potential options for delivery of the model of care

9a	NW London ICS Health and Care Strategy 2023
9b	NW London ICS Health and Care Strategy summary 2023
10	Relevant Trust clinical strategies. No document
11a	NW London ICS Adult community-based specialist palliative care review engagement outcome report March 2023
11b	NW London ICS adult community-based specialist palliative care review. The proposed new model of care engagement outcome report January 2024
11c	NW London ICS adult community-based specialist palliative care review - How are we going to deliver the new model of care - potential delivery options? Engagement outcome report January 2024
11d	How are we going to deliver the new model of care for adult (18+) community-based specialist palliative care services (CSPC) in NW London? Next steps presentation
12a	NHS NW London CSPC programme risk log 29 January 2024
13	Assessment regarding sustainable healthcare considerations and carbon footprint. No document
14a	NW London CSPC Model of Care support letter - St Luke's Hospice 29 January 2024
14b	NW London CSPC Model of Care support letter - Royal Trinity Hospice 29 January 2024
14c	NW London CSPC Model of Care for community specialist palliative care – from CNWL [Central and North West London NHS Foundation Trust]

14d	NW London CSPC Model of Care support letter – Harlington Hospice
15	Financial information in PCBC. Second version of PCBC provided. Available on request.
16	Mapping of previous London Clinical Senate report (29 September 2020) recommendations against current NW London CSPC service improvement programme work
17	NW London Adult Community-based Specialist Palliative Care – our co-designed new model of care: London Clinical Senate 05 March 2024 (Slides from panel day)

Appendix D- London Clinical Senate Review Panel membership and declarations of interest

Name	Roles	Interests Declared
Heather Richardson	Chair of Review Director of Academic Learning and Action St Christopher's Hospice	None
Marianne Leach	Vice Chair of Review Consultant Paediatrician St Georges University Hospital	Nothing to declare
Naureen Bhatti	Retired GP – East London	Nothing noted
Lucy Brett	Chair, Patient and Public Voice Group London Clinical Senate	None
Adrian Capp	Head of Therapies, Queen Square Division University College London Hospital	Nothing noted
Liz Carty (contributed electronically)	Interim Local Postgraduate Dean, NHS England (London)	I am an employee of Barts Health I am seconded to NHS England as Interim Local Postgraduate Dean
Elaine Cloutman-Green	Consultant Clinical Scientist (Infection Control Doctor) Deputy Director of Infection Prevention and Control Joint Trust Lead Healthcare Scientist Honorary Professor, Department of Civil, Environmental and Geomatic Engineering, University College London	Nothing noted
Maurice Cohen	Deputy Medical Director and Consultant Geriatrician, North Middlesex University Hospital NHS Trust Clinical Director London Frailty Network NHS England (London)	None
Natasha Curran	Medical Director, Health Innovation Network Lead Implementation and Involvement Team Applied Research Collaboration (ARC) South London Consultant in Anaesthesia & Pain Medicine, University College London Hospitals	None

Sumeeta Dhir	Southwark GP Primary care clinical lead, Palliative and End of Life clinical network, NHS England (London)	None
Polly Edmonds	Consultant in Palliative Medicine Clinical Director Cancer and End of Life Care Chair, Palliative Medicine Specialist Advisory Committee King's College Hospital NHS Foundation Trust	None
Tim Edwards	Consultant Paramedic Clinical Directorate London Ambulance Service NHS Trust	None
Pauline Fahy (Contributed electronically)	Senior Programme Manager, Health & Care in the Community, NHS England (London)	None
Michael Gill	Chair London Clinical Senate. Consultant Physician, Non-Executive Director Homerton Healthcare NHS Foundation Trust	None
Mark Mason	Medical Director, Heart, Lung and Critical Care Clinical Group, Guys & St. Thomas' NHS Foundation Trust	None
Lucy Pain	Palliative Care Consultant, North London Hospice	None
David Parkins	Chair, London Eye Health Network NHS England (London)	None
Khushboo Patel	Patient and Public Voice Group member, London Clinical Senate	None
Jade Stacey (Contributed electronically)	Implementation Consultant- NICE Field Team (London & South East Region) National Institute for Health & Care Excellence	None
Gladys Xavier	Director of Public Health & Commissioning, London Borough of Redbridge	None

Notes

All Panel members completed Confidentiality and Register of Interests forms.
Where information was given, this has been included above.
Where members left their forms blank this has been transcribed as "nothing noted".

Appendix E – North West London Team

Name	Role
David Harman	Communications Manager, NHS North West London
Andrew Pike	NHS North West London Programme Communications Lead
Michelle Scaife	NHS North West London Local Care, Programme delivery manager for Last phase of life
Jane Wheeler	NHS North West London Local Care Programme Director
Dr Lyndsey Williams	NHS North West London GP clinical lead for Palliative End of Life Care and Care homes

Appendix F- Glossary

This glossary includes frequently used definitions and key concepts that are pertinent to the report. It also confirms the terminology used to describe different groups involved in the process.

We have sought to ensure that all words are written in full before an abbreviation is used in the text. If we have included a quoted which has used an abbreviation, we have included the full word/s in square brackets that follow.

The definitions below have been defined from several sources:

- Where the word or phrase is included in the glossary of the Draft PCBC this has been repeated.
- Where there is a helpful definition readily available by a reputable source on the web, this has been linked
- Other definitions have been agreed with the chairs of the review.

Term	Definition
Bed days	Bed days are the number of days a patient spends in a hospital, hospice, or healthcare facility as an admitted patient staying overnight. For example, if someone is admitted and stays for 3 days, that's counted as 3 in-patient bed days. This is used to see how long patients stay in beds for medical care. The individuals and organisations who commission or oversee these services use bed days as a way to measure and manage healthcare resources. It helps them understand how efficiently hospices and hospitals are working. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Co-design	Co-design is the method of involving users (people), stakeholders (decision makers) and practitioners (front line staff) in the process of service design. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Care Quality Commission (CQC)	The Care Quality Commission is the independent regulator of health and social care in England. Care Quality Commission (cqc.org.uk)
Community-based specialist palliative care (CSPC)	Community-based specialist palliative care refers to providing specialised care for individuals with life-limiting illnesses and those close to them outside of a hospital, typically in their own homes, care homes, or hospices. These services aim to manage symptoms, enhance quality of life, and provide support during the end of life process. The

	goal is to collaborate with patients and their loved ones, tailoring care to meet their specific needs and wishes, and ultimately improving the overall quality of their life and death. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
EMIS (originally Egton Medical Information Systems)	Clinical software used by many GP practices
End of Life Care	End of life care is a specific type of care for individuals nearing the final stages of their life. It aims to ensure comfort, dignity, and support, managing symptoms and providing emotional and practical assistance. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Generalist palliative and end of life care	Generalist palliative and end of life care is the fundamental level of palliative and end of life care support provided by healthcare professionals such as a general practitioner (GP), community nurses (including district nurses), care home staff, therapists, domiciliary home care staff (for example care agency staff either arranged by the council, through continuing health care or privately) and hospital ward staff who have a general understanding of and training in palliative care. They provide support to patients with serious illnesses or nearing the end of life in their usual place of residence (which may be their home, a care or nursing home or a sheltered housing facility) or a medical facility such as a hospital or hospice. The majority of people with life-limiting and advance illness will only need this level of support through their journey of palliative and end of life care. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Home and usual place of residence	What we mean when we say home or usual place of residence is a place in the community where a patient life most of the time and feels comfortable. It's where a patient has their own space and belongings and normally live most of the time/ spend the majority of their days and nights. It's the place you call home. It could be an apartment, house, hostel or shelter, dedicated care setting (care home (nursing, residential, learning disability care home), sheltered housing and supported living accommodation and mental health facility) where you have a consistent living arrangement at this place. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)

Integrated Impact Assessment (IAA)	An Integrated Impact Assessment is a process that brings together a variety of impact assessments on health, equalities, travel and access, and sustainability.
Integrated Care Boards (ICBs)	Integrated care boards (ICBs) replaced clinical commissioning groups (CCGs) in the NHS in England from 1 July 2022. An integrated care board (or ICB) is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Integrated care systems (ICSs)	Integrated care systems (ICSs) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. The NW London ICS consists of all NHS organisations and local authorities in NW London. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
In-reach	In-reach health services are medical services that are delivered to patients who are already admitted or residing in a particular healthcare setting, like a hospital, nursing home, or hospice. Instead of patients going out to seek medical care, the care comes to them within the confines of the facility where they are receiving care or residing. This approach aims to enhance patient access to necessary medical attention, convenience, and continuity of care while minimizing the need for external transfers or travel. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Key Line(s) of Enquiry KLOE	In this context the key lines of enquiry are the questions or areas that the Senate Review Panel identified for exploration with the North West London Team. These were shared in advance of the review day and explored further on the review day.
Local Medical Committees (LMCs)	Local Medical Committees are local representative committees of NHS GPs. They interact and work with the General Practices Committee and well as other branch practice committees and local specialist medical committees

	in a variety of ways, including conferences and in providing guidance for practices. Local medical committees (bma.org.uk)
Multidisciplinary teams (MDT)	A Multidisciplinary Team (MDT) is a group of professionals from one or more clinical disciplines who together make decisions regarding recommended treatment of individual patients. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Model of care	A model of care is a framework that explains what care will be provided and how services work together to deliver care that meets the needs of the population and incorporates best practice. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
NICE	National Institute for Health and Care Excellence NICE are the experts in evidence-based best practice and value for money. Their core purpose is to help practitioners and commissioners get the best care to patients, fast, while ensuring value for the taxpayer. They do this by: • producing useful and usable guidance for health and care practitioners • providing rigorous, independent assessment of complex evidence for new health technologies • developing recommendations that focus on what matters most and drive innovation into the hands of health and care practitioners • encouraging the uptake of best practice to improve outcomes for everyone. Who we are | About | NICE
North West London Team/ NWL Team	The representatives from north west London community specialist palliative care programme who contributed to the review by providing documentation and on the review day. See appendix E for details of members.
Outcome Assessment and Complexity Collaborative (OACC)	The Outcome Assessment and Complexity Collaborative (OACC) is a validated suite of outcome measures that is aimed to measure, demonstrate, and improve care for patients and families.

Palliative care	Palliative care is a treatment, care and support approach that focuses on improving quality of life by managing symptoms, relieving pain, and addressing the side effects of a patients' condition. It also provides support for emotional and practical needs, along with those of family, friends and care givers. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Patient outcomes	Patient outcomes are the results from care and treatments patients have received whilst in hospital, other clinical or care settings. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Pre-consultation business case (PCBC)	The pre-consultation business case (PCBC) is the legal document on which the commissioner decides to consult. Therefore, it must contain all the information they need to make this decision. The PCBC is also used to inform assessment of proposals against the government's four tests of service change, NHSE's fifth test, and other best practice checks. (Major service change: An interactive handbook. NHS June 23. Available from NHS Futures.)
Personalised care planning	Personalised care and support planning is a series of facilitated conversations in which a patient, their family or those close to them can actively participate in exploring the management of the patients' health and well-being within the context of their whole life and family situation. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Senate Review Panel/ The Panel/ Panel	The group of people who contributed to this review including London Clinical Senate Council member, London Clinical Senate Patient and Public Voice members and subject matter experts in Palliative Care. See appendix D for details of members.
Specialist palliative and end of life care	Specialist palliative and end of life care is an advanced and specialist level of palliative and end of life care provided by expert health care professionals who have received specialised training in this field. Care is provided by a specialist palliative care multi-disciplinary team (doctor, nurse, therapist) who work with your regular care teams in the community to provide additional support and guidance for complex symptoms and challenges.

	This type of care is required by individuals with advanced and life-limiting illness that have complex needs (can be medical and social). This care is usually provided in special palliative care units, hospices, or at home/ usual place of residence via the specialist multi-disciplinary team across services. This type of specialist care is not required by everybody with palliative care needs and at the end of life. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Universal Care Plan (UCP)	The Universal Care Plan (UCP) is an NHS service that enables people living in London to have their care and support needs and preferences digitally shared with healthcare professionals across the capital. It is the recommended platform for urgent and end of life care plans in NW London and London. (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Unknown patients	By ‘unknown’ patients, we mean patients who have not previously received care from community specialist palliative care services (and are therefore not registered with, or are unknown, to the services). (Draft pre-consultation business case 29.1.24. Section 17, Appendix F)
Whole Systems Integrated Care (WSIC)	The Whole Systems Integrated Care Dashboards are a suite of tools available to clinicians and care professionals who are providing direct care to patients. The WSIC Dashboards provide a linked integrated summary of patient's health and social care which can be used to case find and case manage patients who require more targeted and proactive care. The Dashboards aim to support clinical staff in improving timeliness and quality of care for patients across NWL London. Whole Systems Integrated Care (WSIC) :: North West London ICS (nwlondonicb.nhs.uk)

Appendix G- Terms of Reference[18]

NHS NW London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care

London Clinical Senate

Terms of Reference

Date: 22 December 2023

Email: england.londonclinicalsenate@nhs.net

Web: www. Londonsenate.nhs.uk

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[18] Terms of Reference wording is consistent with original but for clarity, formatting changes have been made for inclusion in this appendix.

INDEPENDENT CLINICAL REVIEW: TERMS OF REFERENCE

Title	NHS NW London adult (18+) community-based specialist palliative care services improvement programme and proposed new model of care.
Sponsoring Organisation:	NHS North West (NW) London Integrated Care Board
Clinical Senate:	London Clinical Senate
NHS England regional or team:	NHS England – London
Terms of reference agreed on behalf of the London Clinical Senate by:	Dr Mike Gill, Chair, London Clinical Senate Council
Terms of reference agreed on behalf of NHS NWL	Jane Wheeler, Director of Local Care, NHS NW London
Date	22nd December 23

Contents

1. Background

Background provided by North West London ICB:

Palliative care services are designed to address and meet the health and care needs of people with a terminal diagnosis and/or fewer than 12 months left to live. Adult community-based specialist palliative care (CSPC) services deliver for such patients with specialist needs in hospices and the community, and support relatives, carers and people who are important to patients.

National context

The 2019 NHS Long Term Plan committed to improving personalised palliative and end of life care for people of all ages and to address health inequity. In 2022, ICBs received statutory guidance on palliative and end of life care underscoring the Health and Social Care Act 2022 requirement that ICBs have a legal responsibility to commission health services that meet their population needs. Building on *Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026*, it sets out 6 ambitions from the perspective of a person nearing the end of life:

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

Figure 1: Ambitions for palliative and end of life care.

Local context

North West (NW) London ICS Strategy

North West London currently

Our ICS strategic priorities support our intention to review and improve provision of community specialist palliative care (CSPC) in the following ways:

NW London Strategic Priority	How CSPC review responds to strategic priorities of the ICS
Support health and wellbeing for our population	The programme has reviewed provision of services at the end of life from the perspective of patients, carers and families. Our Model of Care sets out how we will support all of these groups, in line with local needs and best practice for these services.
Address unwarranted health inequalities	The programme has examined the variation in CSPC provision within our boroughs. Our Model of Care set out how we will reduce inequality of provision and ensure high-quality services across all Boroughs.
Improve access to care	In addition to ensuring equitable access to high-quality services (see line above), we have assessed the accessibility of our inpatient services to ensure that this is not adversely affected by other changes.
Keep people at home wherever possible and ensure far more integrated/joined up services, particularly for our older people	Our Model of Care includes a comprehensive suite of home-based and community-based palliative care services, including 'hospice at home' provision, alongside hospice inpatient services. It also includes holistic assessment of patient needs, and subsequent co-ordination of care provision, by a specialist palliative care team.
Support babies, children, and young people to lead happy and healthy lives, and become happy and healthy adults	Not applicable. This programme relates only to adults.

Ensure our health and care system is as productive and high quality as it can be	As part of the programme, we have assessed both what CSPC services should be provided in NWL in order to ensure high-quality care, and what level of provision will be needed to meet population needs (ensuring value for money).

The transformation programmes described in the NW London ICS strategy include the 'Local Care programme' which is responsible for improvements in palliative care. The programme seeks to better join up health and care support for residents. As such, the programme also focuses on the building blocks that underpin service delivery: partnerships, pathways, digital and data, and estates.

The NW London Community Specialist Palliative Care Programme will develop and implement the future NW London model of care, working closely with our residents, partners and providers.

The current provision of these services in NW London is a complex arrangement of commissioning, including lead commissioner arrangements, and joint funding with non-NHS 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 (LNW).
- **Combined NHS and charitable funded providers -** St Luke's Hospice, Marie Curie Hospice, Harlington Hospice, Royal Trinity Hospice and St John's Hospice.

The link between service providers to North West London and our eight boroughs is described below:

Borough	NW London's commissioned community-based specialist palliative care service providers by borough 1 April 2023- 31 March 2024
Brent	• St Luke's Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John's Hospice
Ealing	• London North West University Healthcare NHS Trust providing Meadow House Hospice
Hammersmith & Fulham	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John's Hospice

Harrow	• Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services
Hillingdon	• Harlington Hospice (including provision of Michael Sobell House in-patient unit at Mount Vernon Hospital) • Central and North West London NHS Foundation Trust
Hounslow	• London North West University Healthcare NHS Trust providing Meadow House Hospice
Kensington & Chelsea	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John's Hospice
Westminster	• Royal Trinity Hospice • Central London Community Healthcare NHS Trust providing Pembridge Palliative Care Services • St John's Hospice

Case for change:

Details regarding the Adult community- based specialist palliative care (CSPC) review were published in November 2021by **North West London Integrated Care System (NW London ICS)** published an **Issues Paper** that set out eight reasons why community-based specialist palliative care services for adults needed to be improved in North West London, if everyone was to receive the same high level quality care regardless of their circumstances.

These eight reasons were to:

1. Build on the valuable learning and feedback received from previous reviews of palliative care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, Westminster and further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.
2. Align with national policy such as the national Six Ambitions for Palliative and End of life Care and the NHS triple aim of improving access, quality and sustainability.
3. Address the changing demographics and needs of patients. The number of deaths within England and Wales will rise by an additional 130,000 deaths each year by 2040, and more than half of which will be people aged 85 years or older leading to increased need for community-based specialist palliative care.
4. Tackle health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.

5. Address variation in the quality and level of community-based specialist care that patients, families and carers receive across NW London which means not all get the support they need and are able to have their wishes supported at the end of their lives.
6. Some of our services are fragmented, not joined-up and do not work well together - not all services having access to clinical information held electronically by other providers. People sometimes find services hard to access, particularly across our more diverse communities, which cannot continue.
7. Take into account the increasing financial challenge the NHS is operating under and what it means for community-based specialist palliative care.
8. Recognise the difficulty we are having finding, recruiting and retaining a suitably qualified workforce and the knock on effect for service delivery. Local data on exact staff shortages among our providers is not available but it is frequently reported in discussions.

An underpinning issue is that provision of hospice inpatient care at Pembridge palliative care services inpatient unit was deemed unsafe due to poor staffing levels in 2018. As a result, care provision was suspended in October 2018 with patients instead accessing inpatient care through other providers to North West London via spot-purchase of this additional hospice inpatient bed capacity.

The **Issues Paper** was designed to facilitate discussions between patients, families and carers, clinicians and stakeholders. We wanted people to tell us of their experiences and we wanted to jointly agree what high quality, safe, equitable care looks like and just as important what excellent patient experience looks like.

Following a widespread engagement exercise we published an **engagement outcome report** that contained all of the feedback given following discussions with local residents and those who have first-hand experience of palliative and end of life care received in NW London.

Turning the case for change into action

In 2022 a model of care working group was set up by the NW London ICS to co-produce a model of care with the input of bereaved people, carers, clinicians and providers. The intention was to respond to the issues highlighted above. The group met 38 times, successfully concluding their discussions in June 2023. The output of this group, the proposed new model of care describes the level of care that all residents should expect to receive, not where or how these services will be delivered.

The resulting model of care has also been agreed by the **NW London community- based specialist palliative care steering group.**

We subsequently published the **proposed new model of care** in late August 2023 and have continued to engage on it with our residents, boroughs and stakeholders over September and early October 2023.

By and large there was good support for the proposed new model of care, however we did hear some valuable challenge and constructive suggestions on how we might improve the model, which we are committed to considering and potentially incorporating as part of the model's improvement process.

The following are some of the key themes arising from engagement on the proposed new model of care that will be considered in refining the final model:

- Improved navigation of services
    - Emphasis on simplifying the complex journey through palliative care services and the wider health and care system for patients, family/ carers and clinicians to make the services more accessible to those in need, which could include enhanced information resources for accessibility and navigational assistance for example a single point of access at NWL or local "place" level.

- Enhanced Care Coordination and Integration of services:
    - Emphasis on the need for more seamless transitions between acute and community services, through more integration and co-ordination across acute specialist and community specialist palliative care services, but also within realm of community palliative care services itself (spanning both generalist and specialist care providers) and social care services, particularly at local "place".
    - Fostering collaboration and improved communication among healthcare professionals to support a localised, patient-centred approach with named care coordinators or a dedicated care co-ordination service/function to improve the overall patient experience and bridge gaps between generalist and specialist care

- Addressing Inequalities:
    - Emphasis on the need to address disparities in access to palliative care service healthcare provision, ensuring that all individuals, regardless of their background or circumstances, receive the same level of high-quality palliative care. Call for more tailored strategies for different communities, considering geographic, socioeconomic, and cultural factors to demonstrate model will support addressing these disparities.
- Enhancing innovation and continuing improvement alongside new MOC implementation:
    - Emphasis on improving the model by exploring innovative initiatives, drawing on local, regional and national pilots underway. Making sure the current model has openness to testing the below ideas (which currently do not have robust evidence to support them being included in the current model) as pilots, whilst the model is

being implemented. To enable evaluation of their effectiveness and support evolving the model over time, making make sure that palliative care services continue to adapt and improve to meet the evolving needs of the NW London communities and any possible future requirements from NHSE:

    - Emergency department support via in-reach and rapid response, with aims to reduce admissions
    - co-ordination service
    - single point of access
    - virtual hospice (which could include specialist MDT support)
    - support for rapport discharge

- Improved leadership and governance:
  - Emphasis on robust leadership and governance structure to guide the transformation and for accountability and sustainability of the new care model.

- More information about enhanced end of life care beds
  - Emphasis on there needing to be more detailed and clear explanation of what exactly is being offered in terms of these beds and how they will be made available to ensure that they effectively meet the needs of patients, to ensure that assurances are given that these beds are a suitable and high-quality option for patients, rather than being seen as a subpar substitute for traditional hospice inpatient care.

The proposal

We believe the proposed new model of care offers the opportunity to improve the level and scope of community-based specialist palliative care in every borough in North West London.

The new model shows “what good care should look like” for adults (18+) across NW London. Some of these services already exist across all boroughs, while others are new additions and will level up the standard of care. This is particularly significant for boroughs where the services currently do not exist or there is significant variation for boroughs.

The model covers a wide range of community-based specialist palliative care services that will help patients to stay in their own home or usual place of residence, whilst allowing them the flexibility to move to a different care setting if needed. It increases the range and number of inpatient bed care options available by introducing enhanced end of life care beds, for people with less complex specialist palliative care needs who still require inpatient care. This is on top of the existing hospice inpatient beds currently in place and projected to be required over the next five to ten years.

The model also includes an extension of a number of existing services to level-up provision and availability across all eight NW London boroughs, including:

- Extended provision of 24/7 telephone advice lines for existing and unknown patients

- Extended days and hours of care provision (7 day services, 8am to 8pm a change from 5 day services 9 to 5pm) by community specialist palliative care teams
- Increased support to care homes from community specialist palliative care teams
- Expansion of Hospice at Home services to all boroughs (currently have 3 of 8 boroughs without this service available at all), with an expansion of current service offer to routinely support up to 24-hour care in patients' homes if needed
- The introduction of new common standards for psychological and bereavement support services
- Expansion of lymphoedema services, to ensure that we have non-cancer and cancer lymphoedema support available for all boroughs.

Specific recommendations

The model of care working group have collectively agreed and recommended a set of core services for community-based specialist palliative care provision that NW London residents can expect to receive regardless of the borough they live in. Some of these services are already available to all boroughs, while others are new additions for some boroughs and will raise the standard of care where these services do not exist or vary a lot.

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

The recommended model of care has three key service areas, each providing different services to meet patient needs. These would deliver the following for all NW London adult residents for the first time:

Service area 1: Care at home

- Adult community specialist palliative care team:
    - 7-day service with working hours of 8 am - 8 pm – this is a change from 9am - 5pm working hours and some services (Harrow) only operating 5 days a week at present.
    - Increased support to care homes – common core level of training and support.
- Hospice at home:
    - Supporting up to 24-hour care at a patient's home (including overnight sitting services) in close collaboration with usual community care teams. This is currently not being provided across all existing services.
    - Expansion of services to additional boroughs currently without this service: Hammersmith & Fulham, Ealing, and Hounslow.
- 24/7 specialist telephone advice line:

  - A common core service for patients who are already known to community-based specialist palliative care services as well as those who are unknown patients.
  - This is a change from current 24/7 specialist palliative care advice line services, which in the main only support known patients and have variation in the level of advice and support offered.

Service area 2: Community specialist in-patient beds

- An increased number of beds in the community, which includes dedicated enhanced end of life care beds available across all of NW London for patients who either do not require a hospice bed but cannot stay at home due to medical and social needs, or who do not wish to stay at home, or who do not want to, or do not meet the need to be in a hospital.
- Maintaining the current number of operational hospice in-patient unit beds to support our patients with the most complex specialist palliative care needs.

Service area 3: Hospice out-patient services, hospice day care services and well-being services (including psychological and bereavement support services for patients and families)

- Whilst all our boroughs currently have access to hospice out-patient clinics, hospice day care services and well-being services via their local providers, variation in the level of support provided was identified. We aim to make sure hospice out-patient multidisciplinary team (MDT) clinics (including but not limited to medical and nursing clinics, rehabilitation via therapists, and dedicated lymphoedema services) deliver the same core level of service. This refers particularly to the boroughs of Ealing and Hounslow where doctor and nurse led clinics are currently not available via Meadow House Hospice, as well as Harrow where there is currently a gap in provision of lymphoedema services for non-cancer patients. We propose to expand lymphoedema service provision for these non-cancer patients in Harrow.

- We aim to make sure well-being services (including hospice day care support groups, family and carer practical support and education, complimentary therapies, and dedicated psychological and bereavement support services deliver a core level of service. Particularly for psychological and bereavement support services for patients, their families, carers and those important to them which includes a more streamlined pathway to access these services, increased personalisation of care for example offering one-to-one and group sessions, face-to-face and virtual support, and increased cultural and spiritual sensitivity to delivery of this care and support. While all boroughs currently have access to some psychological and bereavement services, this varies in level of support.

The key enablers that will help us deliver the new model of care

A key feature in the feedback we received from local people was the need to make sure we put in place effective ways of working and the systems and processes that are needed to support the delivery of high quality palliative and end-of-life care. There was a particular emphasis on the need to reduce health inequalities, have a palliative care workforce (generalist and specialist) that is both sustainable and understands the cultural and faith requirements of our diverse communities.

We have identified five key enablers that we will need to develop and put in place to support the successful implementation and delivery of our recommended new model of care, and achieve the improvements in care we are able to deliver:

- Workforce development
- Reducing inequalities
- Data, digital and technology
- Organisational development
- Leadership, governance and integration

Work is being undertaken to scope and define the various task and finish groups for each of the enablers between September and October 2023.

Engagement and progressing to options for delivery of the proposed new model of care

Since the release of the proposed model of care in late August 2023, we have undertaken engagement seeking input from the public on the proposed new model of care throughout the summer and early October 2023.

However, engagement on the overall model of care will continue beyond this as we progress to business case development, potential public consultation and implementation of any agreed changes.

We have also:

- Developed a long-list of options for delivery of the new model of care with the steering group then conducting the initial shortlisting.
- We know that many of the 54 longlisted options will not deliver the level of change we know is needed, and so they would not be acceptable to our residents
- We therefore applied four ‘hurdle criteria’, developed by the NW London CSPC steering group, to ensure that we systematically eliminated options that would not deliver the outcomes we want
- We have been engaging on these options with our residents throughout November 2023.

Next steps:

- There have been a number of delays to the programme as we have sought to maintain an open engagement approach. We had hoped to be able to discuss the business case with the senate earlier in the Autumn.
- During winter 23/24 we are intending to publish a revised version of the proposed new model of care incorporating the feedback from this engagement.
- We have been advised by a number of our Local authority overview and scrutiny committees that they would like a full public consultation process around the proposed options for delivery of the proposed new model of care. We are therefore applying to the London Clinical senate for their advice and guidance to support the assurance process which is required to commence a full public consultation later this year, which will be subject to approval from local borough Overview & Scrutiny Committees/ NW London Joint overview and scrutiny committee.

2. Aims of the review and advice requested

The Clinical Senate will review the draft PCBC in advance of submission of the final PCBC to NHSE in accordance with the major service change assurance processes.

This planned approach will enable **NHS NW London** to make best use of Clinical Senate advice and recommendations, integrating them where appropriate into the final version of the PCBC, prior to the assurance process.

In accordance with the agreed timeline, the draft PCBC will be provided to the clinical senate no later than midday 29/01/24.

Specific areas where advice is requested from Clinical Senate:

NHS North West London are requesting advice and support from the Clinical Senate to provide comment / advice on

a. Is the clinical case for change supported by best evidence and practice guidance?
b. Does the proposed new model of care and potential options for implementation improve the quality and outcomes for the community served?
c. Are the levels of stakeholder engagement and the processes for the engagement conversations held so far sufficient to support formal consultation process?

3. Scope of the review

“Planning, assuring and delivering service change for patients” (NHS England, updated March 2018) requires NHS England to be assured that any proposal for major service change or reconfiguration satisfies four tests set by the Government in 2010:

- Strong public and patient engagement
- Consistency with current and prospective need for patient choice
- Clear, clinical evidence base

- Support for proposals from commissioners

In 2017 the NHS Chief Executive introduced a 5th new patient care test for hospital bed closures, specifying that alternative provision is in place before any beds are closed.

The clinical senate's advice will be focused on the third test of clinical evidence and the fifth 'beds' test as relevant. It is also cognisant of London Mayor's tests and encourages commissioners to consider their response to these in developing their Consultation Business Case

The London Mayors 6 tests, introduced 6 tests in 2017 were designed to ensure that the changes are in the best interests of Londoners. These are conditions that must be met before the mayor will support any major health and care transformation or service reconfiguration in London.

The 6 areas, which are considered post consultation are:

- Health and healthcare inequalities
- Hospital Beds
- Financial investment and savings
- Social care impact
- Clinical Support
- Patient and Public Engagement

These were refreshed in late 2022, with key changes being:

- Strengthening the health inequalities test and additional supplementary question that highlights the role of the NHS
- Recognising new opportunities afforded through the use of digital healthcare within the Hospital Beds test.

In Scope for this NWL London review are:

- Community-based specialist palliative care services for Adults (18+) – provided by NHS trusts and charitable hospice providers – including services such as hospice inpatient bedded care, hospice at home, community specialist palliative care nursing teams, 24/7 advice lines, outpatient and well-being services.

Out of scope for this NW London review are:

- 'Universal' services that support generalist palliative and end of life care needs – general practice, district nursing, the Universal Care Plan – although recommendations on integration and UCP underpinning advance care planning to be undertaken by community-based specialist palliative care services are made.
- Children and young people
- Views raised by the public as part of engagement on assisted dying/ euthanasia

4. Principles for improving quality and outcomes

The Clinical Senate Council has also agreed a set of principles which it believes are essential to improving quality of care and outcomes. The Council seeks evidence of, and promotes, these principles in the issues it considers and the advice that it provides.

They are:

- Promoting **integrated working across health and across health and social care** and ensure a seamless patient journey
- Being **patient-centred and co-designed** (this includes patient experience, patient involvement in development and design of services)
- Reducing **inequalities** (this involves understanding and tackling inequalities in access, health outcomes and service experience, between people who share a protected characteristic and those who do not, and being responsive to the diversity within London's population)
- Demonstrating **parity of esteem between mental and physical health** for people of all ages
- Supporting **self-care** and **health and wellbeing** Improving **standards and outcomes** (these include use of evidence and research, application of national guidance, best practice and innovation)
- Ensuring **value** (achieving the best patient and population outcomes from available resources)
- Demonstrate how **environmental sustainability and moves to carbon neutral** are included in plans and developments. This includes reference to the National ambition to reach carbon Net zero by 2040 and the London Health Board ambition to ensure that every Londoner breathes safe air.

5. Review Panel

The clinical senate will complete a review via Microsoft TEAMS

Chair

The panel will be chaired by members of the London Clinical Senate Council:

Heather Richardson, Education, Research and End of Life Policy Lead, St Christopher's Hospice

The Deputy Chair will be Marianne Leach, Consultant Paediatrician, St Georges University Hospital

Overseen by Dr Mike Gill, Consultant Physician, Chair London Clinical Senate Council and Non-Executive Director Homerton University Hospital NHS Foundation Trust

Membership

Membership of the review panel will be multi-professional. Its members will have expertise in the services and pathways being considered. Subject to agreement with the Chair, membership will include expertise independent of **NHS NW London** that are unrelated to the changes proposed. Advice on membership will be sought from the London Clinical Senate Council with relevant expertise, and professional bodies as necessary.

The review panel will seek advice from other independent experts on specific issues if indicated. The review panel will not include anyone who has been involved in the development of the proposals being considered or associated with the bodies.

Conflict of Interests

All review panel members will be required to formally declare any interests (which will be noted in the review report) and sign a confidentiality agreement.

6. Method and Approach

In determining the review approach and formulating advice the Clinical Senate Council and Review Panel will draw on the following, which includes guidance on testing an evidence base:

- Clinical Senate Review Process: Guidance Notes, NHS England, August 2014
- NHS England's Service Change Toolkit
- Planning, assuring and delivering service change for patients, NHS England, March 2018

The review is expected to involve the following steps:

Step 1: **Establish the review panel**

Step 2: **Brief the review panel** and circulate key documentation

Step 3: Hold a **review panel meeting** to:

a. agree the overall methodology applied to formulate the advice
b. identify issues that need to be explored, clarified or validated to assist in formulating the advice
c. agree any further information/documentation required to inform the review

Step 4: Hold an expert **review panel** on the 5th March 2024 via Microsoft to undertake the following:

a. Meet and discuss the proposals/solutions with stakeholders (commissioners and providers) involved in their development to explore key lines of enquiry
b. Provide an opportunity for stakeholders impacted by the proposals to share views with the review panel
c. Debate findings within the review panel and finalise conclusions
d. Identify any outstanding issues and agree the process for following up (and further review panel discussion as agreed necessary)

Step 5: **Prepare a report** setting out overall findings, conclusions, advice and any recommendations. This will be circulated to the review panel and if required, a meeting agreed to discuss matters of accuracy and agree amendments.

The sponsoring organisations will be provided with a copy of the draft report for a factual accuracy check.

Step 6: Once agreed by the review panel**, share the report with the Clinical Senate Council** who will:

- Ensure the terms of reference have been met
- Comment on any specific issues where identified by the review panel
- Agree that the report can be issued

Subject to the schedule of Council meetings the Senate Council Chair may undertake this on the Council's behalf.

Step 7: **Issue the report.**

7. Documentation required by the Clinical Review Panel

In formulating advice, the review panel will review documentation that has both informed and been developed by commissioners.

Where possible relevant sections/pages of documents should be highlighted where the whole document does not apply to the proposals or context of a Clinical Senate review.

The documentation that it is anticipated will inform this review is listed below. Further requirements may be confirmed following establishment of the review panel.

- The draft Pre-Consultation Business Case (PCBC)
- The Case for Change (rationale for the proposed change and evidence base)
- Proposed clinical models (description, rationale and evidence base)
- Supporting activity and workforce data and modelling, patient flows and pathways, patient transport, performance against key quality indicators benchmarking data/patient experience data – available information should be provided initially, and any further specific requests will be discussed
- Relevant CQC [Care Quality Commission] inspection and GIRFT [Getting It Right First Time] reports
- Schedule of evidence and best practice that have informed the proposals
- Equality impact assessment
- Alignment to ICB plans
- Relevant Trust Clinical Strategies
- Process used to develop the proposals including staff, service user and public involvement
- Summary of outcomes of patient and public engagement
- Summary of outcomes of stakeholder engagement, including neighbouring trusts and services
- Programme risk log
- Assessment regarding sustainable healthcare considerations and carbon footprint

The review panel will formulate the advice requested based on consideration and triangulation of the documentation provided, discussion with key stakeholders and panel members' knowledge and experience. The advice will be provided as a written report.

8. Timeline

- **Convene a go no go meeting for 8th December. Documentation availability is confirmed.**
- **Clinical senate to convene panel with 8 weeks' notice.**
- **Submit draft PCBC and associated appendices to clinical senate for review no later than 29th January 2024**
- **5 March 2024. Review to be undertaken via Microsoft Teams**

- **1st April 2024 final draft clinical senate report and recommendations issued to NWL for MoA check.**
- **15th April 2024 Final report issued.**

9. Risks

It is essential that the processes through which the Clinical Senate formulates advice are robust and the approach outlined is designed to do this. Recruiting the appropriately experienced review panel members who are available on the key dates set for the review and ensuring adequate time to prepare for key activities are the most critical elements and pose the greatest risk. Every effort will be made to mitigate this risk.

10. Reporting arrangements

The review panel will report to the Clinical Senate Council who will agree the report and be accountable for the advice contained in the final report. The chair of the council may sign off the report pending formal noting at the council meeting.

The Clinical Senate Council will submit the report to the sponsoring organisation and this advice will be considered as part of the NHS England assurance process for service change proposals.

11. Report

A final draft report setting out the advice will be shared with the sponsoring organisation to provide an opportunity for checking factual accuracies prior to completion. Comments/corrections must be received within 5 working days.

Communication and media handling

North West London ICB will be responsible for publication and dissemination of the report. The expectation is that it will be made publicly available as soon as possible following completion. The London Clinical Senate will post the report on their website at a time agreed with the sponsoring organisation.

Communication about the clinical review and all media enquiries will be dealt with by the sponsoring organisation.

If helpful, the Clinical Senate will support the sponsoring organisation in presenting the review's findings and explaining the rationale for the advice provided e.g. at a key stakeholder meeting subject to discussion and availability of review panel members.

Disclosure under the Freedom of Information Act 2000

The London Clinical Senate is hosted by NHS England and operates under its policies, procedures, and legislative framework as a public authority. All the written material held by the Clinical Senate, including any correspondence sent to us, may be considered for release following a request to us under the Freedom of Information Act 2000 unless the information is exempt.

12. Resources for the review

The London Clinical Senate will recruit review panel members and cover members' reasonable expenses. It will also provide management support to the review panel, including coordinating all communication relating to the review, documentation sharing, meeting organisation and report production.

The sponsoring organisation will identify a named contact to coordinate the provision of documentation and any other information requested and to assist in coordinating stakeholders' participation in the review at a local level. The sponsoring organisation will also organise accommodation for meetings and the review panel day.

If during the course of the review the review panel identifies any additional requirements to formulate the advice requested, the review Chair or Clinical Senate Senior Project Manager will, if necessary, discuss these with the sponsoring organisation and may seek resources for this.

13. Accountability and Governance

The review panel is part of the London Clinical Senate's accountability and governance structure.

The Clinical Senate is a non-statutory advisory body and will submit the review report and its advice on the proposals to the sponsoring organisation. The sponsoring organisation remains accountable for decision making. The review report may draw attention to specific issues, including any risks, which the Clinical Senate believes the sponsoring organisation should consider or address.

If the Clinical Senate identifies any significant concerns through its work which indicate risk to patients it will raise these immediately with relevant senior staff in the organisation(s) involved. Please note that depending on the nature of the issues identified the Clinical Senate Council may be obliged to raise these with the relevant regulatory body(ies). Should this situation occur, the Clinical Senate Council Chair will advise the Chief Executives, Clinical Leads and Chief Officers of the provider and commissioning organisations involved.

14. Functions, responsibilities and roles

The sponsoring organisation will:

- Provide the review panel with the proposed PCBC, and associated resources.

- Respond within the agreed timescale to the draft report on matters of factual inaccuracy.
- Undertake not to attempt to unduly influence any members of the review panel during the review.
- Submit the final report to NHS England for inclusion in its formal service change assurance process.

The **London Clinical Senate Council and the sponsoring organisation** will:

- Agree the terms of reference for the clinical review, including scope, timelines, methodology and reporting arrangements.

The **London Clinical Senate Council** will**:**

- Appoint a review panel which may be formed of members of the Senate, external experts, and/or others with relevant expertise.
- Endorse the terms of reference, timetable and methodology for the review.
- Consider the review recommendations and report (and may wish to make further recommendations).
- Provide suitable support to the review panel.
- Submit the final report to the sponsoring organisation.

The **review panel** will:

- Undertake its review in line with the methodology agreed in the terms of reference.
- Submit the draft report to the London Clinical Senate Council for comment, consider any such comments made and incorporate relevant amendments into the report. Review panel members will subsequently submit a final draft of the report to the London Clinical Senate Council.
- Keep accurate notes of meetings.

The **review panel members** will undertake to:

- Commit fully to the review and attend/join all briefings, meetings, interviews, panels etc. that are part of the review (as defined in the methodology).
- Contribute fully to the process and review report.
- Ensure that the report accurately represents the consensus of opinion of the review panel.
- Comply with the confidentiality agreement and not discuss the scope of the review nor the content of the draft or final report with anyone not immediately involved in it.
- Declare to the review panel Chair any conflict of interest prior to the start of the review and/or any that materialise during the review.

15. Contact details of key personnel coordinating the review process

For the London Clinical Senate:

Head of London Clinical Senate

Email address: emilywebster@nhs.net / robin.plata@nhs.net

Please also include the following email address in correspondence england.londonclinicalsenate@nhs.net

For NHS North West London:

Name: Jane Wheeler

Title: Director of Local Care, NHS North West London

Email address: jane.wheeler2@nhs.net

Name: Michelle Scaife

Title: Programme delivery manager Last phase of life, NHS North West London

Email Address: michelle.scaife@nhs.net

Name: Andrew Pike

Title: Head of communications, NHS North West London

Email address: a.pike@nhs.net

Name: Dr Lyndsey Williams

Title: NW London GP clinical lead for palliative and end of life care, and care homes.

Email address: lyndseywilliams@nhs.net

Please also include the following email address in all correspondence **nhsnwl.endoflife@nhs.net**