Brent	**Community and Wellbeing Scrutiny Committee** 5 July 2022
	Report from NW London Integrated Care System

End of Life Care

Wards Affected:	All
Key or Non-Key Decision:	Non-Key
Open or Part/Fully Exempt: (If exempt, please highlight relevant paragraph of Part 1, Schedule 12A of 1972 Local Government Act)	Open
No. of Appendices:	None
Background Papers:	None
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1. Purpose of the Report

1.1 The report provides the Community and Wellbeing Scrutiny Committee with an outline of the community based specialist palliative care improvement programme.

2. Recommendations

2.1 The Committee are asked to note the content of the report.

3. Detail

3.1 Detail outlined in the main body of the report below.

North West London
Integrated Care System
Working together for better health and care

Community-based specialist palliative care improvement programme

Brent Council Community and Wellbeing Scrutiny Committee 5 July 2022

www.nwlondonics.nhs.uk/get-involved/cspc

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Appendix 1 – Detail on the Palliative care services improvement programme in the London Boroughs of Brent, Hammersmith & Fulham, Kensington and Chelsea and Westminster.

1 Introduction

Working together with residents, the London Borough of Brent and other councils across North West London (NW London) it is going to be critical to ensure we best meet the needs of those who require community-based specialist palliative care.

The North West London Integrated Care System (NW London ICS) is acutely aware that the ambiguity on the Pembridge Palliative Care Centre inpatient unit is problematic and we need to ensure we reach a clear and sustainable future for services in Brent and NW London, whilst developing a new model of care that delivers a safe and clinically high standard service that meets the needs of patients and at the same time and addresses inequalities across NW London.

We are undertaking a NW London exercise so we can learn good practice across our eight boroughs and meet the ICS objectives around equality of access, experience and outcomes, however within that the specific concerns and needs in each borough are important.

This paper describes the overall NW London approach but seeks to draw out for Brent specifically

- Outputs of local engagement sessions - see page 25.
- Data relevant specifically to Brent and your services/residents – see page 20.
  Details on the area we know to be of most ongoing concern – and our efforts to address this – see page 16.
- See page 10 for information on the suspension of Pembridge services and work to address the workforce challenge.

We will continue to engage with Brent residents, stakeholders and teams to ensure the outputs of this review work for Brent, and will deliver improvements in the experience of your residents, their family and carers.

We welcome the chance for a discussion today on the balancing of these issues. When we come to mutual decisions we need to know they are backed up by robust engagement and that we have worked through the pros and cons transparently.

Key points for Brent and NW London

- The NW London ICS wants to work with patients, carer and families and other stakeholders to understand how we can improve the experience for all adults who use community specialist palliative care services in North West London.
- A North West London wide steering group has been established that consists of NHS providers, hospices, local authority and resident representatives. Our Issues Paper sets out the key reasons why we are looking at community-based specialist palliative care and helps us have a conversation on what future care could look like.
- An engagement period started on 18 November 2022 and was extended to mid-March due to Omicron – during the winter key partners were largely deployed to the immediate response and as such the pause in work was regrettable but unavoidable. Further engagement has/is occurring to ensure

that all boroughs have the opportunity to have discussions including the Brent, Harrow and Hillingdon event that took place on the 17 March 2022 and the Brent engagement event that took place on 15 June 2022.

- An interim engagement outcome report was published on Thursday 9 June 2022 which contained all 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. We would like to thank all those who have taken part. The report will be revised as further feedback is received with a final report published at the end of July 2022.
- The outcome report was sent to stakeholders across NW London including council and NHS leadership, MPs and Healthwatch. We also used our established channels to communicate with other stakeholders and North West London residents. We also produced a short video to accompany the launch and a newsletter that has been distributed widely as well.
- All the public feedback received will be used by our model of care working group, which is responsible for designing, planning and mobilising the future model of care for adult community-based specialist palliative care.
- Membership of this group consists of local residents, clinicians and other palliative and end of life care stakeholders. The group will be asked to:
    - agree a common specification / common core offer for community-based specialist palliative care.
    - develop a new model of care to deliver the specification / common core offer.
    - map out how this can be implemented in each borough.
- The work will draw on the national service specification for adult palliative and end of life care, the previous NW London palliative care review programme work and qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement. We will also utilise activity trend data obtained through the programme’s data working group and undertake further work looking at the structure of our services workforce.
- The expected output is a set of core service standards, requirements and service functions that will need to be delivered across NW London. There will also be a number of additional localised requirements that the local Borough Based Partnerships will have responsibility for implementing these in view of their local context and population needs.
- We will work with the Integrated Care Partnerships, local residents and stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If substantial service change is needed, we will then need to consider if a public consultation is needed.
- Moving forward, our expectation is that there will be wide ranging resident and stakeholder involvement throughout this process. If significant service change is proposed, we would undertake a formal consultation.
- The inpatient unit at Central London Community Healthcare NHS Trust’s (CLCH) Pembridge Palliative Care Centre continues to remain suspended until further notice following its closure due to a lack of specialist palliative care consultant cover and being unable to recruit due to that national shortage of trained personnel. It takes significant consultant resource to run and oversee an inpatient unit and based on current capacity CLCH would not be able to run this safely. All other services (24/7 advice line including palliative care consultant support, community specialist palliative care nursing service, rehabilitation team support service, social work and bereavement support

service, and day hospice services at the Pembridge Palliative Care Centre are unaffected and continue to operate.
- Along with a number of unsuccessful attempts to recruit consultants, we have sought to work across the system to ‘network’ consultants in hospitals and hospices to support reopening Pembridge beds, but have not been able to develop a clinically supported model to do that – this challenge is underpinned by a national workforce shortage.
- In April 2020, the inpatient beds at Pembridge were temporarily re-designated for the for rehabilitation of Covid positive patients. We were able to staff the service – which was not consultant led- because we had national guidance to pause many other services. It is unlikely that Pembridge will be required to fulfil this function again due to the knock on impact on those other services.
- We do recognise that local residents are disappointed with the need to suspend this inpatient service and confirm that a decision on the future of the unit will only take place following the completion of the community-based specialist palliative care review that the North West London Integrated Care System is leading and is currently underway.
- We confirm that qualitative factors such as local accessibility and stakeholder views will be an important consideration alongside quantitative factors such as capacity and referrals when making any decisions regarding future provision of community-based specialist palliative care service in NW London including the future of the Pembridge in-patient beds.

We share with Brent Council and residents a focus on palliative care because of the importance of getting care and service provision right

“"We have seen what a difference specialist palliative care services can make to a patient and their families and carers as they come to the end of their life but unfortunately we have seen what can happen if the care and support is not there and the damaging legacy for those left behind. That is why it's important that we work together to develop services that are clinically to a high standard but also meet what patients and family’s need."

Dr Lyndsey Williams,
NW London GP Clinical Lead for End of Life and Care Homes

It is widely recognised that when caring for someone in the last year of their life, we have only one chance to get it right.

Anyone at the end of their life should be able to live and be cared for where they want to be and be with the people they want to be with. They (and their family, loved ones and carers) deserve the best quality care and support, regardless of their circumstances. We live in a rapidly ageing society, where people are living longer but are more likely to live with multiple complex long term conditions. As a result, the need for high-quality palliative and end-of-life care is expected to increase dramatically by 2040.

> “We need to remember how scattered families can be and how people in theory would often like to think of dying at home, and so would their families. But the reality and the lack of properly seamless care means that it becomes an impossibility or can lead to a very, very negative death. The repercussions upon individuals of experiencing negative death of somebody they care about go on to have psychological and other repercussions throughout their lives.”
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> **Quote from member of the public attending the engagement event on 13 December 2021**

Too many people experience poor care as they approach the end of their life, with many people spending their last months and weeks in hospital, often dying there, which may not be what they want. Not only can this be distressing for the patient and their loved ones, but it also adds more pressure on acute hospitals.

Palliative and end-of-life care is a national priority, as well as a priority for health and social care partners across North West London. In North West London we have some excellent palliative and end-of-life care services for adults (aged 18 and over), provided by very committed partner organisations, but we know that we need to improve the care we provide in hospitals, community settings (such as hospices and day centres), primary-care settings and patients’ own homes. We want to make sure all patients have equal access to accessible, consistent, high-quality care across all palliative and end-of-life care services.

More also needs to be done to make sure the care provided by different organisations is more joined up. This includes looking at the IT challenge of not all services having appropriate access to clinical information held electronically by partner providers for patients under their care; and making sure all patients have a personalised care plan that has been agreed with them, and that the plan is available to the different care sectors supporting them and their family.

2 Our focus on community-based specialist palliative care

We are focused on community based specialist care for adults at this stage because of the fragility of those services.

In North West London we have eight community-based specialist palliative care providers providing services. These include seven hospices with inpatient units, as well as separate community specialist palliative care nursing services.

The providers deliver a wide range of services (including inpatient and community-based specialist palliative care nursing, day hospices and outpatient services) as well as some additional specialist services (including lymphedema, well-being services and complementary therapies).

Three providers – Central London Community Healthcare NHS Trust, London North West University Healthcare NHS Trust and Central and North West London NHS Foundation Trust – receive all their funding from the NHS. The other five providers are charitable hospices and receive their funding from a combination of NHS and charitable income.

- Royal Trinity Hospice is based in South London. It provides services to parts of Hammersmith & Fulham, Westminster and Kensington & Chelsea.
- St John’s Hospice is based in Westminster. It provides services to Brent,
- Hammersmith & Fulham, Westminster and Kensington & Chelsea. It is located in St John’s Wood on the St John and St Elizabeth’s Hospital site.
- Marie Curie Hospice is based in Hampstead and provides services to Brent.
- Marie Curie’s London Nursing Service provides end-of-life rapid response and nursing services to Ealing and Hounslow.
- St Luke’s Hospice is based in Harrow. It provides inpatient and other hospice services to Harrow and Brent, with their community specialist palliative care nursing team only providing cover to North Brent.
- Harlington Hospice is based in Hillingdon. It also provides the Michael Sobell hospice inpatient unit which is located at the Mount Vernon Hospital in Hillingdon. Both services serve Hillingdon.
- Meadow House Hospice is based at Ealing Hospital, and is run by London North West University Hospital Trust. It provides services to Ealing and Hounslow.
- Pembridge Palliative Care Service is in North Kensington. It provides services to Hammersmith & Fulham, Westminster, Brent (South) and Kensington & Chelsea (please note, the inpatient bed part of this service is currently suspended).
- Harrow Community Specialist Palliative Care Team is also provided by Central London Community Healthcare NHS Trust, and provides services in Harrow only.
- The Hillingdon Community Palliative Care Team and Your Life Line Service are provided by Central and North West London NHS Foundation Trust. These services are provided in Hillingdon.

The NHS and its partners are committed to making improvements in community-based specialist palliative care for adults within this review process, but will continue to seek to improve other areas of palliative and end-of-life care where possible in parallel.

Beyond this review there are opportunities for improvement across the wider palliative care landscape

We also want to raise awareness of the importance of palliative and end-of-life care in general, and discuss what we want to see in the future from high-quality, safe, community-based specialist palliative care for adults, which also delivers an excellent patient experience. We want to:

- Make sure everyone receives the care they need, when they need it, regardless personal characteristics such as their gender, ethnicity, social standing or where they live (this is known as equity of access), and improve the quality of care our residents and their families and carers receive.
- Improve the experience for our patients, and their families and carers, by developing services that reflect what is important to them at the end of their lives, from diagnosis through to death.

We are not reviewing children's and young people's palliative and end-of-life care services, community nursing which provides generalist palliative and end-of-life care services, or acute hospital services which provide specialist palliative care services.

However, we will be working hard to make sure that our work links closely and joins up with hospital specialist palliative care and all other generalist palliative and end-of-life care services in North West London. We will also work with a number of NW London ICS's other service-improvement initiatives that are already looking to reduce differences in and improve the quality of non-specialist (generalist) palliative and end-of-life care services. This includes the NW London Community Nursing Review and NW London Enhanced Health in Care Homes programme.

Difference between generalist and specialist

Palliative and end-of-life care can be generalist or specialist. By community-based specialist palliative care services, we mean care and support services that are not provided in an acute hospital, GP surgery or by district nurses or community matrons. Instead, they are provided in a patient's own home, a care home, a hospice, a community hospital or health centre by specially trained multi-disciplinary teams.

Specialist palliative care professionals, such as palliative care doctors, nurse specialists, therapists and psychologists, are experts in providing palliative and end-of-life care and have specific training and experience. They usually become involved in a patient's care to help manage more complex care problems that go beyond the expertise and knowledge of a patient's generalist and usual care team (for example, their GP and district nurses). They work closely with the patient's GP and district nurse to offer advice on controlling pain and managing symptoms, provide emotional and practical support for patients, their loved ones and carers in preparing for the end of their life and, after the patient dies, offer bereavement support to their loved ones.

Generalist palliative and end-of-life care is provided on a day-to-day basis by many health and social care professionals, such as GPs, district nurses, social workers and care home staff. A patient’s family and carers can also provide generalist palliative and end-of-life care in the patient’s home.

We are starting by ensuring a shared view of the different issues that we are trying to solve

There are eight broad reasons why we need to improve the way we deliver our community-based specialist services to ensure everyone receives the same level of high-quality care, regardless of their circumstances.

1. To build on the valuable learning and feedback received from previous reviews of palliative and end-of-life care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster, and the further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.
2. To bring services in line 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, and to make sure providers our aligned to the National institute of Care and Excellence (NICE) guidelines for palliative and end-of-life care services.
3. To meet patients’ changing needs arising from changes in the population. By 2040, the number of deaths within England and Wales is expected to rise by 130,000 each year. More than half of the additional deaths will be people aged 85 or older, so there will be an increased need for palliative and end-of-life care services.
4. To reduce health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.
5. To make sure that everyone receives the same level of care, regardless of where they live. At the moment there are differences in the quality and level of community-based specialist care that patients, families and carers across North West London receive. This means that depending on where a patient life, they and their family and carers may not get the support they need, and may not be able to have their wishes supported at the end of their life. We want to do all we can to make sure this is not the case.
6. To make it easier for people to access services, particularly across our more diverse communities. Some of our services are not joined up and do not work well together, and we need to change this.
7. To cope with the increasing financial challenge, the NHS is facing and the effect this has on community-based specialist palliative care.
8. To reduce the difficulty, we are having finding, recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services.

3 Pembridge Palliative Care Service

Whilst the eight issues above are relevant to all boroughs, in Brent there is particular interest in the future of Pembridge Palliative Care Service provided by CLCH

When Pembridge inpatient unit was suspended in 2019 we committed to completion of the review prior to any decisions were made on the future of this unit. It is regrettable that the period of time where we have focused on Covid response and recovery has impacted on the timeline for completing this work. Whilst acknowledging the local frustrations on the lack of clarity for the future, we remain committed to do this review properly so there is a clear process and transparency on next steps.

Pembridge Palliative Care services during Covid pandemic waves one and two

As part of a system response to support Covid-19 patients the Pembridge inpatient beds were designated to support the rehabilitation and care of Covid positive patients.

- During the first wave the inpatient unit was opened on 20 April 2020 and closed again on 30 July 2020.
- During the second wave the inpatient unit was opened on 16 November 2020 and closed on 26 March 2021.

Other service elements of the Pembridge Palliative Care Services were operating as follows:

- The community specialist palliative care team continued to offer a 7 day a week service running 8.30am to 5pm Monday to Friday, 9am to 5pm Saturday, Sunday and Bank holidays. The community team were prioritising patients with uncontrolled complex symptoms that have not responded to previous treatments, and actively dying patients with no previous plan of care in place.
- 24/7 advice line including specialist palliative care consultant support.
- Day hospice and patient attendances to the hospice were suspended. Patients known to the service were receiving telephone advice and support from the clinical team.
- The social work and bereavement team suspended visiting and outpatient sessions, but continued to operate, receiving new referrals and providing telephone advice and support.
- The Pembridge teams moved to video conferencing services where possible to further support patient care.

Pembridge Palliative Care service now

The Pembridge Palliative Care Services inpatient unit remains suspended, but the following other services elements continue to be provided:

- Community specialist palliative care nursing team, seven days a week visiting service 8.30am - 5pm Monday to Friday, 9-5 weekends (Saturday and Sunday) and Bank Holidays.
- 24/7 advice line including palliative care consultant support.

- Rehabilitation team support -visiting and virtual from Occupational Therapist (OT), Physiotherapist (PT) and Rehabilitation Assistant five days a week (Monday – Friday).
- Social work and bereavement support, five days' week (Monday –Friday);
- Day Hospice Services Monday – Friday during Covid as many of these services as possible were offered virtually.

NW London ICS End of Life programme team monitors the number of patients who would have been eligible for inpatient care at Pembridge and instead are supported in a different unit. During 21/22 (extrapolated from nine month's data) this was 25 patients. Largely, these patients receive care at St John's Hospice which is part of the St John and St Elizabeth's Hospital and located in St Johns Wood, with a much smaller number at Royal Trinity Hospice. Further work needs to be undertaken to understand if the service closure has resulted in a fall in the number of patients accessing inpatient beds, as well as the impact of Covid-19 across all hospices as a whole.

Over the recent Covid outbreaks our NW London hospices and other community specialist palliative care services have shown considerable flexibility and joint working to provide system support, such as flexing criteria to support discharges. We have consistently had spare bed capacity in NW London hospices (with the exception of a short period during the recent Omicron variant where staff sickness impacted across health and social care services).

In July 2021 prior to relaunching this North West London wide review of community – based specialist palliative care, a number of palliative medicine consultant vacancies arose across three of our palliative care providers, including Pembridge Palliative Care Service, St John's Hospice and Imperial College Healthcare NHS Trust (ICHT). We undertook project work with these providers to review the service requirements for their consultants and how these might be met through new models of consultant service delivery for specialist palliative medicine within community, hospice and hospital domains to ensure a more resilient and sustainable workforce collaboratively. As part of this work we looked to identify if there was, two years on any other potential solutions to the Pembridge consultant workforce challenge to support safe running of the inpatient unit.

Through this work we engaged with a number of NHS Trusts and hospices, both inside and outside of North West London on their consultant models. We learnt that flexibility, rotation between care domains, career progression, being part of clinical network and organizational culture are all important in attracting and retaining consultants. It was also noted that across London and nationally there are palliative care consultant workforce vacancies and shortages, with many organisation struggling to fill and retain these posts.

Despite substantial input from all partners on this work, at that time we could not identify any collaborative solutions that did not destabilise one service to stabilise another. The outcome was that each organisations proceeds to recruit independently to the posts, as the solution would need more dynamic transformation work to address the palliative care workforce challenge, which is not just synonymous to these three organisations. This issue would therefore best be addressed within the North West London wide Community-based specialist palliative care review programme and development of a new model of care, including palliative care workforce.

We reiterate that no decision has been taken on the long-term role of Pembridge and as part of this review the important function that is inpatient palliative care will be addressed. We also recognise the impact this has on individuals and families of those who need to use alternative services elsewhere.

4 Building on feedback previous done

We must build on feedback previously given – valuing people’s time and views, by showing progress where ever possible

When we talked to people about community-based specialist palliative care services previously, we heard what a crucial role the services play. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We have also heard that services need to be made available to more people 24 hours a day, particularly that out-of-hours services (those provided between 5pm and 9am) need improving to make them more inclusive and adaptable, and to offer more choice and be more co-ordinated. People told us it is important to improve access to these services so more people receive care and are supported to die in their preferred setting, whether this is at home, in a hospice or in hospital. It is also important that people don’t have to travel too far to access service.

> Mum wanted to die at home and was told that there were drugs that would be needed and they’d arrange for these to be prescribed. I then got a call from the palliative care team the next day to tell me they’d sent the prescription to mums nominated chemist. When I got there, I was told one item wasn’t in stock and they’d order it. When I got outside I realised it was the pain relief which is what I needed the most and I had to run around trying to get it.”
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> **Example from a bereaved resident on the challenges of integrated care**

The feedback showed that people have different views on how we should make these improvements. We want to build on the feedback and what we have learnt from it. We also want to fully understand the role culture and religion can play in influencing the way people relate to their health, the support they want to receive and the way they experience loss and grief. We will then use this insight to develop services that can take this into account.

5 Next steps

We cannot resolve the current situation and issues unless we work in partnership with residents and other stakeholders –we welcome Brent support to do this

We want to work with local residents, clinicians and partners from volunteer, community and faith organisations to jointly identify and decide what high-quality community-based specialist palliative care looks like. We will then develop a new model of care for our community-based specialist palliative care prvoision that broadly defines the way that services are delivered, in a way that can be maintained, is culturally sensitive and better meets our diverse population's needs. The new model of care must be affordable and financially sustainable in the short and long term and will be delivered across the whole of North West London to make sure that everyone receives the same consistent high standard of care.

Understanding the problem we are trying to solve = The Issues Paper

Agreeing 'Model of Care' - what we need to have in place

Agreeing any impact on services, how they are resourced and delivered

This involves a respectful and responsive approach to the health beliefs and practices, and cultural and linguistic needs, of diverse population groups. However, it goes beyond just race or ethnicity and can also refer to characteristics that are protected by the Equality Act, such as a person's age, gender, sexual orientation, disability and religion, and also social exclusion and socio-economic deprivation (deprivation caused by factors such as being unemployed or on a low income, or living in a deprived area), education and geographical location. (For more information, visit www.equalityhumanrights.com/en/equality-act)

When we have completed our research and received everyone's feedback, we will look to develop the model of care that will deliver the high-quality safe and fair care that people deserve. Our next step will be to look at what services are needed in the future to deliver this new high-quality model of care, that is not only affordable, but sustainable in in the long term, and to bring forward proposals that set this out.

So, for now, we are not looking at or discussing what current community-based specialist palliative care services look like or what their future should be, or how many beds we need in a community setting. That will come in due course when we have agreed what good-quality care looks like and the model of care we need to develop in order to provide it.

In summary, we are having a conversation about what we need to do to improve the quality of care our residents and their families and carers receive when they need community-based specialist palliative care.

From this starting position, we want to work with patients, clinicians and the wider community to develop and introduce a new model of care which is fairer, more joined up, high quality and can be maintained in the long term. It must also meet the clinical and individual needs of patients from diagnosis through to the end of their life, and reflect the choices that people want to make on the care they receive and where they receive it.

6 Insight report

We understand it is really frustrating for people to provide feedback, not see any action, and then be asked again for their views

We have received a tremendous amount of feedback which we are responding to and have taken to date. There are also some areas we are currently developing and implementing or propose to do in partnership, to address the issues raised to support improved care and support for patients, families and carers in the last phase of life. We also detail feedback received where we do not feel able to take action, with the reason for that given.

Our aim is to continue to work collaboratively with our public, patients, clinicians and other system partners to build on this work as it is a key part of the next phase of this programme when we look to explore the model of care and service design options to meet our NW London population's community-based specialist palliative care service's needs.

Feedback	Action taken
• Align GPs more closely with individual care homes and develop enhanced care service for care home residents. • This needs to include the development of personalised care plans to support their care needs and expressed wishes and involve relevant health professionals and the families and carers in these care planning conversations in as much as possible.	• As part of the PCN Direct Enhanced Service (DES) all care homes in NW London have a named GP and where possible are aligned to a single PCN. We are currently working on developing a NW London wide common core standard that will provide enhanced support to care homes and cover the provision of Multi-Disciplinary Team (MDT) working and personalised care and support planning. This includes advance care planning and use of Coordinate my Care/Urgent Care Plan.
• Increased access to end of life and anticipatory medication in the community. Community Pharmacists should be included in the engagement and review process to understand the issue of availability and timely access to end of life medication for patients, families / carers and clinicians in the community.	• Not all boroughs had the same level of in and out of hours' access to end of life care and anticipatory medication. The gap in West London, Central London and Hammersmith & Fulham boroughs was closed by commissioning an equivalent service meaning that during the pandemic all NW London residents have equal access to these medications 24 hours a day. The NW London Medicines Management Team have recently reviewed the service contracts and are putting plans in place to ensure ongoing 24-hour access to end of

	life and anticipatory medications in the community. • NW London has implemented the Pan-London Symptom Control Medicines Authorisation and Administration (MAAR) Chart, developed by the End of Life Care Clinical Network . This MAAR chart supports safe administration of complex injectable regimens.
Feedback	**Action being take**
• Include clinicians in public engagement meetings and patients in programme working groups for the purpose of transparency and trust.	• During the previous review of palliative care that took place in Brent, Hammersmith & Fulham, Kensington & Chelsea’s and Westminster in 2020, we had a clinical reference group who worked on development of the new model of care and options. We did not have any public and patient representation on this group. For this programme we have developed a model of care working group that will have public, clinical and operational lead representatives.
• Access to 24/7 end of life care advice and support for patients, families, carers and clinicians, which includes a single point of access and co-ordination service. This is of particular importance during the out of hours period between 5pm and 8am when the patient may be experiencing a lot of pain and the family and carer may not be able to contact the usual care team or know which services to contact for support.	• All of the hospices that provide services in NW London now provide 24/7 nurse led advice lines that have 24/7 palliative care consultant support. • A further gap was identified for the Harrow Community Specialist Palliative Care team who did not have seven day working and visiting available. We have secured funding to support the development of this service and work is underway to mobilise this as soon as possible.
Feedback	**Action we propose to take**
• Having hospice inpatient services locally is very important, particularly for residents where the spouse, carer and family of the patient requiring hospice inpatient care is elderly or has family and work commitments and are negatively impacted by increased travelling time. Consideration should be given to re-opening the Pembridge inpatient service as part of the service review.	• This programme will be reviewing the role specialist palliative care inpatient beds play in community-based specialist palliative care provision so that we understand the level of need and capacity required across NW London using data to support this work. Discussions about the level of need and sites will happen at a later stage in the review once the new model of care has been developed.
• Not enough support available or consistent offer of bereavement	• Bereavement care and support really came to the fore as a gap

support (pre and post death) available to patients, families and carers. Could this reviewed as part of the latest programme of work to understand current provision and what more could be done to improve this offer.	nationally, regionally and locally during the Covid-pandemic. Through the community-based specialist palliative care review programme we will be scoping current provision and gaps for NW London which will then be considered as part of the new model of care development work.

Feedback	**Reason why we are not able to take action at this stage**
• We have heard from local residents and stakeholders that they would like the NHS to reopen the Pembridge Palliative Care Unit in-patient beds.	• The inpatient unit at Central London Community Healthcare NHS Trust’s (CLCH) Pembridge Palliative Care Centre continues to remain suspended until further notice following its closure due to a lack of specialist palliative care consultant cover and being unable to recruit due to that national shortage of trained personnel. • It takes significant consultant resource to run and oversee an inpatient unit and based on current capacity CLCH would not be able to run this safely. All other services (24/7 advice line including palliative care consultant support, community specialist palliative care nursing service, rehabilitation team support service, social work and bereavement support service, and day hospice services at the Pembridge Palliative Care Centre are unaffected and continue to operate. • In April 2020, the inpatient beds at Pembridge were temporarily re-designated for the for rehabilitation of Covid positive patients. We were able to staff the service – which was not consultant led- because we had national guidance to pause many other services. It is unlikely that Pembridge will be required to fulfil this function again due to the knock on impact on those other services. • We do recognise that local residents are disappointed with the need to suspend this inpatient service and confirm that a decision on the future of the unit will only take place following the completion of the

	community-based specialist palliative care review that the North West London Integrated Care System is leading and is currently underway. • We confirm that qualitative factors such as local accessibility and stakeholder views will be an important consideration alongside quantitative factors such as capacity and referrals when making any decisions regarding future provision of community-based specialist palliative care service in NW London including the future of the Pembridge in-patient beds.

Moving forward, we will continue to update the Insight Report and the actions we have taken as a result. You can find the most up to date Insight Report here.

7 Overview of data for Brent for past 5 years (2017 – 2022)

From the outset it is important to articulate transparently that data availability and reliability are a challenge in terms of end of life data. The data we have used necessarily comes from multiple sources as we work towards a longer goal of having the data joined up in one place.

We are currently developing our future model of care, looking at current service activity data across all care domains, the data available on numbers of deaths and the workforce we currently have in our community specialist teams. We anticipate this will also involve review of demographic data available. In conjunction with a review of the literature around capacity and ultimately the agreed specification this work will allow us to articulate what our future capacity needs to be and see where our resource needs are greatest across NW London.

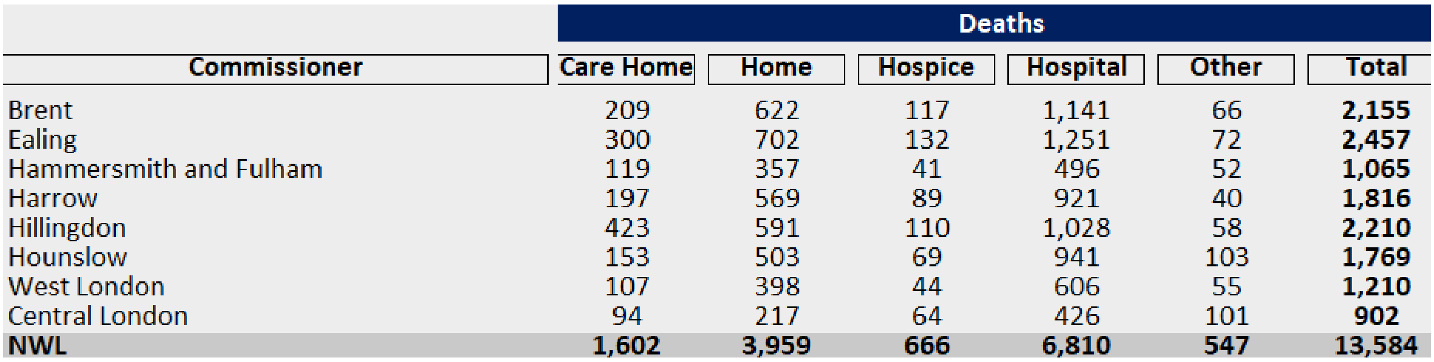
We will be fully transparent with this work and share our outputs and recommendations with borough partnerships to support decision making.

Mortality Data & Demographics

We have utilised the mortality data from 2021 to give an indication of where residents who have died by setting of care and the current demographic data that is also available around this.

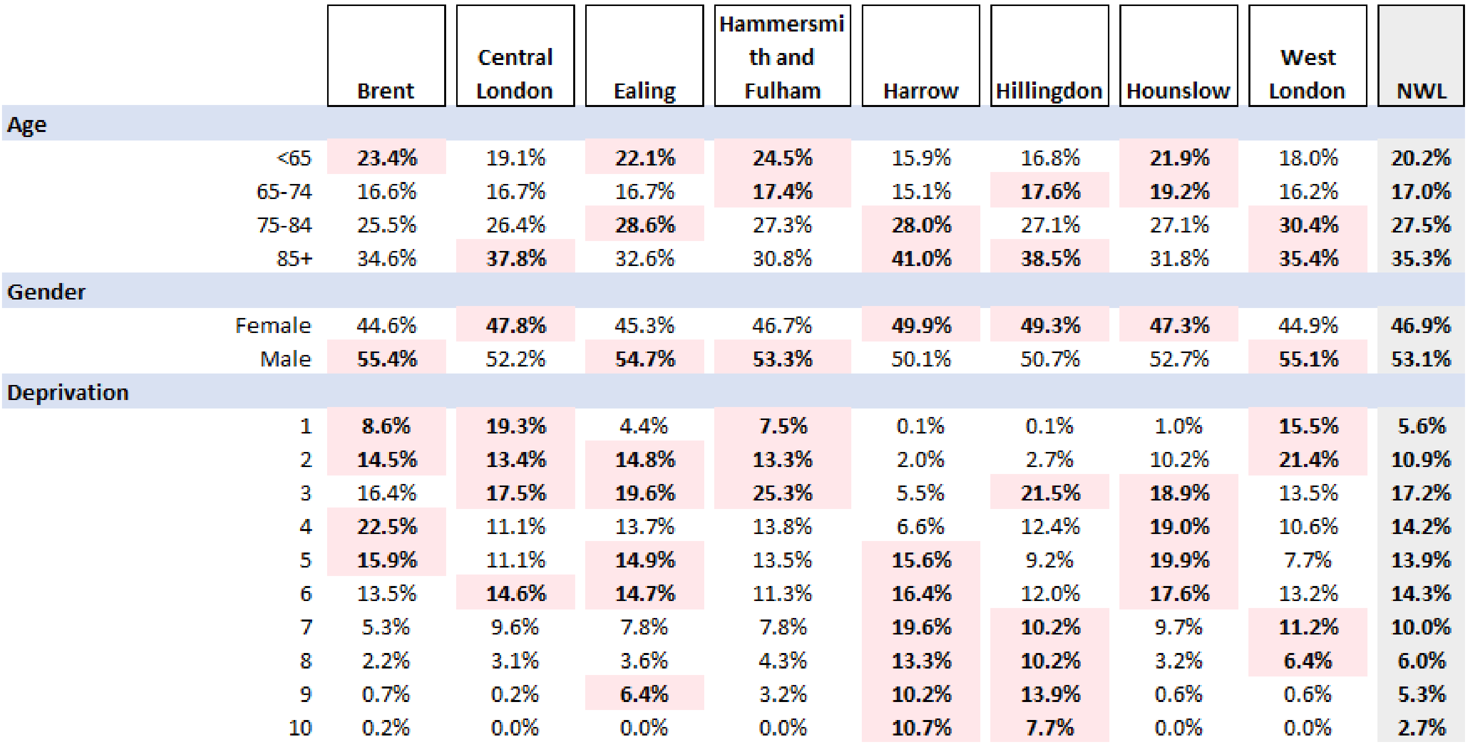
Figure 1 shows a breakdown of all deaths in North West London by setting. Clearly the majority of people died at hospital, whilst a secondarily large number died at home.

Figure 1: Deaths in NW London



	Deaths					
Commissioner	**Care Home**	**Home**	**Hospice**	**Hospital**	**Other**	**Total**
Brent	209	622	117	1,141	66	**2,155**
Ealing	300	702	132	1,251	72	**2,457**
Hammersmith and Fulham	119	357	41	496	52	**1,065**
Harrow	197	569	89	921	40	**1,816**
Hillingdon	423	591	110	1,028	58	**2,210**
Hounslow	153	503	69	941	103	**1,769**
West London	107	398	44	606	55	**1,210**
Central London	94	217	64	426	101	**902**
NWL	**1,602**	**3,959**	**666**	**6,810**	**547**	**13,584**

Figure 2: Deaths in NW London, by age, gender and deprivation



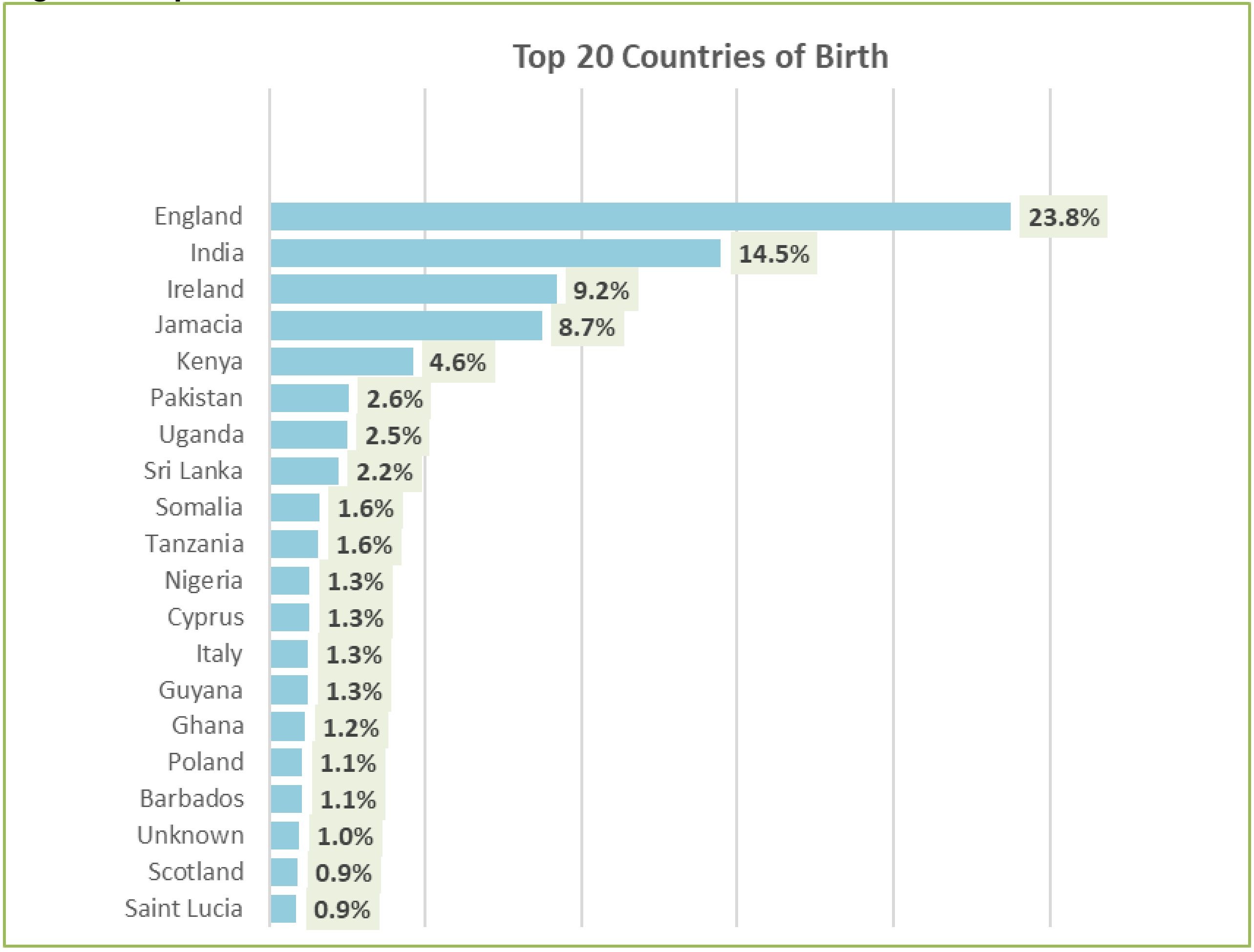
	Brent	Central London	Ealing	Hammersmith and Fulham	Harrow	Hillingdon	Hounslow	West London	NWL
Age									
<65	**23.4%**	19.1%	**22.1%**	**24.5%**	15.9%	16.8%	**21.9%**	18.0%	**20.2%**
65-74	16.6%	16.7%	16.7%	**17.4%**	15.1%	**17.6%**	**19.2%**	16.2%	**17.0%**
75-84	25.5%	26.4%	**28.6%**	27.3%	**28.0%**	27.1%	27.1%	**30.4%**	**27.5%**
85+	34.6%	**37.8%**	32.6%	30.8%	**41.0%**	**38.5%**	31.8%	**35.4%**	**35.3%**
Gender									
Female	44.6%	**47.8%**	45.3%	46.7%	**49.9%**	**49.3%**	**47.3%**	44.9%	**46.9%**
Male	**55.4%**	52.2%	**54.7%**	**53.3%**	50.1%	50.7%	52.7%	**55.1%**	**53.1%**
Deprivation									
1	**8.6%**	**19.3%**	4.4%	**7.5%**	0.1%	0.1%	1.0%	**15.5%**	**5.6%**
2	**14.5%**	**13.4%**	**14.8%**	**13.3%**	2.0%	2.7%	10.2%	**21.4%**	**10.9%**
3	16.4%	**17.5%**	**19.6%**	**25.3%**	5.5%	**21.5%**	**18.9%**	13.5%	**17.2%**
4	**22.5%**	11.1%	13.7%	13.8%	6.6%	12.4%	**19.0%**	10.6%	**14.2%**
5	**15.9%**	11.1%	**14.9%**	13.5%	**15.6%**	9.2%	**19.9%**	7.7%	**13.9%**
6	13.5%	**14.6%**	**14.7%**	11.3%	**16.4%**	12.0%	**17.6%**	13.2%	**14.3%**
7	5.3%	9.6%	7.8%	7.8%	**19.6%**	**10.2%**	9.7%	**11.2%**	**10.0%**
8	2.2%	3.1%	3.6%	4.3%	**13.3%**	**10.2%**	3.2%	**6.4%**	**6.0%**
9	0.7%	0.2%	**6.4%**	3.2%	**10.2%**	**13.9%**	0.6%	0.6%	**5.3%**
10	0.2%	0.0%	0.0%	0.0%	**10.7%**	**7.7%**	0.0%	0.0%	**2.7%**

The deprivation score= 1 is most deprived and 10 least deprived

Figure 2 (above) shows deaths by borough and NW London average split by age, gender and deprivation. Where highlighted red this indicates that the proportion is above the NW London average. In Brent death rates amongst the most deprived residents are generally higher, and has a higher level of deaths amongst deprived residents compared to other boroughs in North West London. Interestingly Brent also has the highest rate of death amongst the under 65s and a higher proportion of deaths are men, compared to other North West London boroughs.

Figure 3 (next page, below) shows the top 20 countries of birth for those that died in Brent in 2021. This has limitations as there is significant ethnic diversity amongst those born in the UK, however, it does give a level of insight, for example a significant proportion of deaths were amongst the Indian community and also fairly high amongst the Irish and Jamaican community.

Figure 3: top 20 countries of birth



Community-based Specialist Palliative Care Services provided in Brent:

There are 4 providers of community-based palliative care services that care for Brent residents. Some patients may also attend Meadow House Hospice in Ealing but this is infrequently as data below shows.

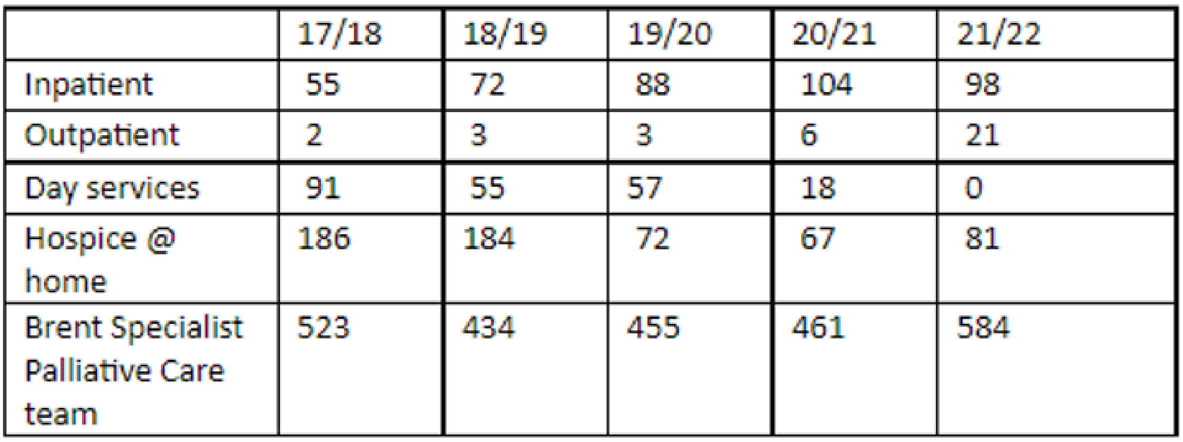
These are specialist providers who for palliative and end of life care, particularly where expert input is required. Please note care in the community patient's receiving these services can also be supported by community nursing (for health needs) and social care (domiciliary care/re-ablement & rehab, housing etc.).

Provider	Location of provider site	Area covered
St. Luke's Hospice	St. Luke's Hospice in Harrow	All of Brent
St John's Hospice which is part of St. John's and St Elizabeth's hospitals	St. John's hospice in St John's Wood	All of Brent
Pembridge Palliative Care Services provided by Central London Community Healthcare NHS Trust (CLCH)	St Charles Hospital in North Kensington	South of Brent
Marie Curie London	Marie Curie Hampstead Hospice in Hampstead	All of Brent

London North West NHS Trust	Meadow House	Considered an out of borough hospice as services for Brent residents are not specifically commissioned from Meadow House Hospice

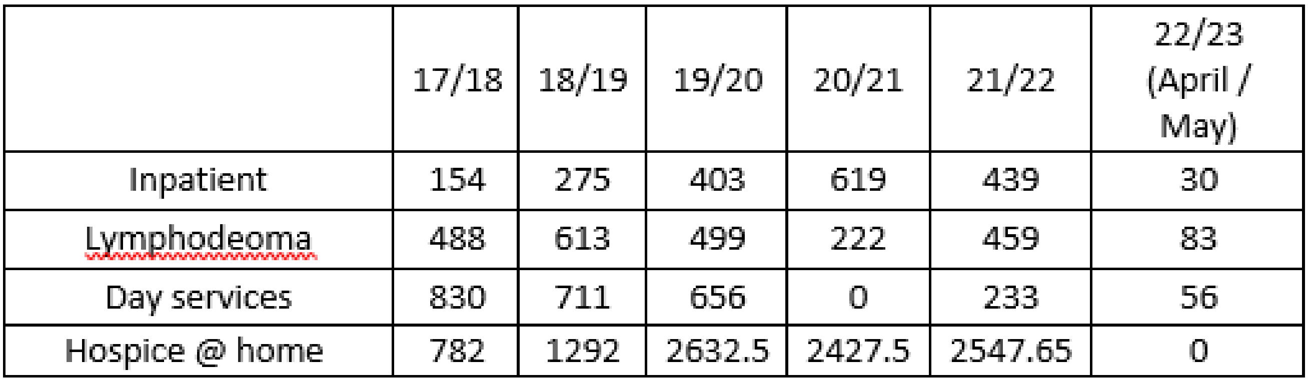
Trends (see figures 4-8), clearly 20/21 there was a rinse in patient use within hospices. This will be due to COVID for two reasons 1) increase in people dying 2) use of hospices as part of our regional bed capacity to support the Covid response. Another trend is that outpatient and day time service activity decreased or even dropped, this will be in line with guidance around infection prevention control measures at the time. **Please note the way the way the data has been captured is slightly different provider to provider so a direct comparison is not advised.**

Figure 4: St Luke's Hospice Activity data (based on number of patients accepted into the services)



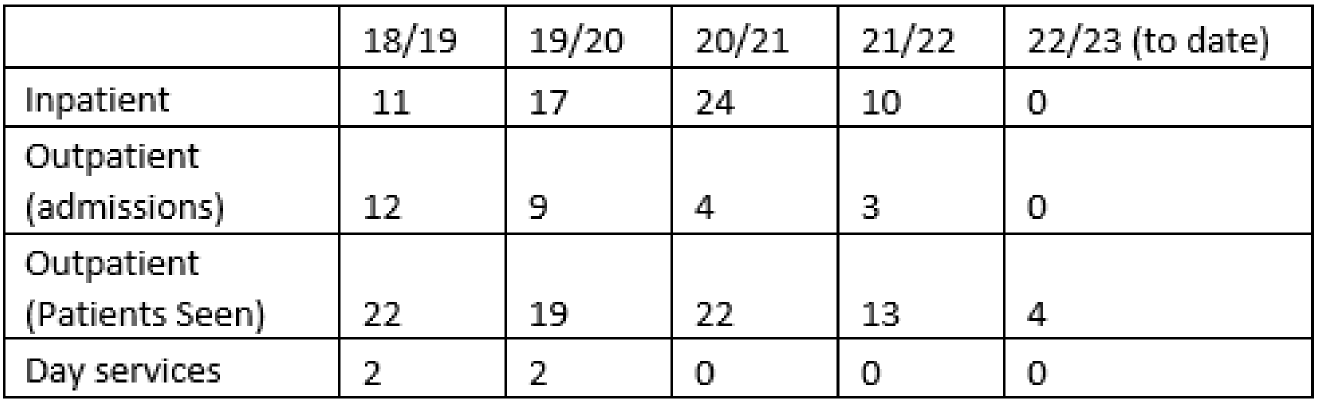
	17/18	18/19	19/20	20/21	21/22
Inpatient	55	72	88	104	98
Outpatient	2	3	3	6	21
Day services	91	55	57	18	0
Hospice @ home	186	184	72	67	81
Brent Specialist Palliative Care team	523	434	455	461	584

Figure 5: St. John's Hospice Activity data (based on number of appointments, bed days and care episodes)



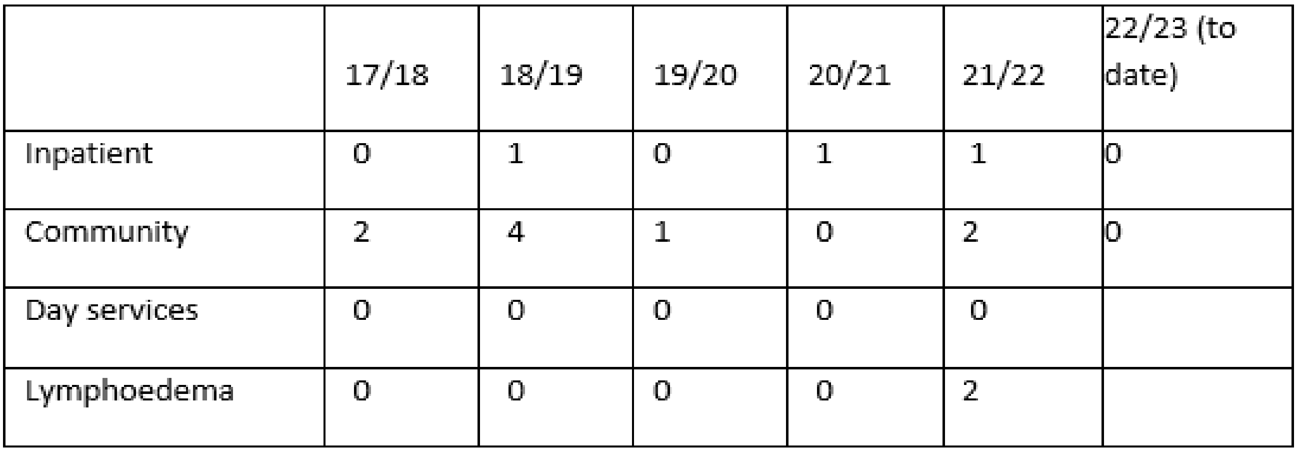
	17/18	18/19	19/20	20/21	21/22	22/23 (April / May)
Inpatient	154	275	403	619	439	30
Lymphodeoma	488	613	499	222	459	83
Day services	830	711	656	0	233	56
Hospice @ home	782	1292	2632.5	2427.5	2547.65	0

Figure 6: Marie Curie Hampstead hospice Activity



	18/19	19/20	20/21	21/22	22/23 (to date)
Inpatient	11	17	24	10	0
Outpatient (admissions)	12	9	4	3	0
Outpatient (Patients Seen)	22	19	22	13	4
Day services	2	2	0	0	0

Figure 7: Meadow house Activity data (based on number of patients accepted into service)



	17/18	18/19	19/20	20/21	21/22	22/23 (to date)
Inpatient	0	1	0	1	1	0
Community	2	4	1	0	2	0
Day services	0	0	0	0	0	
Lymphoedema	0	0	0	0	2	

Figure 8: Pembridge Palliative Care Services (provided by Central London Community Healthcare NHS Trust – CLCH) activity data. This is based on number of patient contacts – Source: CLCH Monthly activity data reports

Years	**18/9**	**18/19**	**19/20**	**20/21**	**21/22**	**22/23 (Apr-May only)**
Inpatient (Bed days)	1118	496	N/A as IPU suspended	N/A as IPU suspended	N/A as IPU suspended	N/A as IPU suspended
Community SPC team (multidisciplinary)	5415	6866	7126	8041	7727	1346
Outpatient						
Day services	615	2691	2942	1751	887	89
Hospice @ home						
Bereavement service	954	1127	890	715	320	89

8 Engagement in Brent

We held two public involvement events with a Brent focus. The first was held on 17 March 2022 and included Brent and Hillingdon residents. The second event was held together with the Brent Integrated Care Partnership on the 15 March 2022. The presentations and recordings of both events can be found online at www.nwlondonics.nhs.uk/get-involved/cspc/how-get-involved.

Engagement with Brent residents will continue as we move forward and we would welcome Brent Council's support and suggestions as we move forward.

Public involvement event 17 March 2022 aimed at ethnic minorities Brent, Harrow & Hillingdon

The need for improved communication both between different parts of the health service and between the different service providers and patients/families/carers was consistently raised. As part of this, improved information sharing, particularly in relation to EOL plans (e.g. CMC) was highlighted on a number of occasions.

Challenges around language, faith and culture were raised in the discussion and highlighted by specific examples participants gave.

Dying at home vs hospital vs hospice

- Dying at home can cause logistical challenges for different faith groups, such as receiving death certification when a GP is not available. For example, a Muslim family, known to a participant had to travel to get a death certificate signed by the GP in a car park so as to bury their family member the next day.
- Therefore, seen as better/easier to die in a hospital environment for some faith groups as they (the hospitals) have the infrastructure and cultural competence to better serve their needs (although there are also issues where you may have multiple family members trying to visit the hospital to pay last respects).
- Many patients may say they wish to die at home but even with 3x nurse visits a day and night support it can be exhausting for the family member(s)/carer who get little sleep or rest. Also, at home it can be very difficult with, for example, pain relief when it's urgently needed out of hours (e.g. 2 am).
- We should note that home environments can differ massively across NW London – some people have small flats not large houses that are not suitable for home care and the hospice environment can be better.
- Caring for a patient at home can be very difficult – people can lack the proper support or facilities (e.g. appropriate bathroom/toilet) at home and struggle to accommodate family visitors.
- Hospices are not tailor made for large visiting groups and can lack the religious aspects certain communities require (e.g. an Imam or Priest who can counsel the patient in final hours and help people/families accept the death of a loved one).
- Carers/families looking after a patient at home can really struggle with a lack of support in out of hours' care.
- In terms of administering drugs at home, and no-one being there when the patient subsequently dies, an attendee pointed to the problem that the police can then end up getting involved.

- What happens to people in hospices that lack family/friends – who sits with them in their final hours and speaks to them / holds their hand?

Help, advice, guidance and information sharing

- The help and information from social workers needs to be improved – with factual advice on what peoples' rights are around death.
- Patients/carers/families need a very simple information sheet saying who to contact and how at different points (e.g. GP, DN service, hospice specialist palliative care service). Importantly, we need to recognise that patients are not just Mon-Fri 9-5. What about outside of that and at weekends and bank holidays?
- We need to improve the links and information sharing between GPs and hospitals.
- There is a lack of consistency in record keeping around preferences, treatment etc.
- The demarcation between health and social care is significant and is not properly understood in the community.
- The most important point is that, in the final hours of someone's life, agreement and coordination with the family is very important – when you are in the grieving process it can be easier if everyone does their job properly and well.
- All patients and families/carers need an up-to-date and fully completed care plan – that they have full access to – this can't be a static document, it has to change as the situation with patient changes.
- The care plan needs to be a living document that the care team, ambulance staff, DNs etc. should all be able to easily access.
- Will the patient and carer/family be able to access the new care planning tool and what is the process for input into it?
- The care plan should be partnership, not just a clinical process. It requires multiple levels of input – from community services, carers etc.
- The carer/friend/family member needs to feel more involved in the process – there needs to be better communication with them.
- There needs to be better post-death bereavement support for carer/family/friends.
- We need a clear final days/hours plan which lists the support available to patients/ carers/families and what they can/should expect (note the additional challenges where the patient has dementia).
- They need information/leaflets etc. – something which clearly breaks down what is available, including exactly what to do out of hours.
- We need to be aware that many patients/families/carers are not compute literature and that people need help with this (in terms of filling in an EOL plan/document but also using email and text).
- The link between the ambulance service and A&E (and other parts of those providing care services) and access to (and use of) existing Coordinate My Care Plan(s) need addressing – the info they need or request should be in these plans and it's shocking that the communications and information sharing are so bad.
- GPs need to have a role in coordinating completion of CMC or the new Urgent Care Plan, this can be complicated by patients rarely seeing the same GP and having chance to build a consistent relationship.
- It would help if families had a single point of contact for their relatives' care.

- System issues

We need a more person-centered approach.

- Hospice success is in consistency and 24-hour approach to patient care.
- We need better collaborative working, training and structures – consistency is paramount and means individual needs will be better understood.
- We need more specialist teams with specialist resources.
- Time is of the essence in terms of making system changes to improve the situation and current experiences.

Specific needs of different groups

- It's felt it's easier to deal with the more established faiths (suggestion that there are at least 15 different religious groupings across NW London).
- Younger members of faith groups can be less aware of the faith's requirements around death (e.g. next day cremation) – they need social care professionals to help them with this as well.
- There are questions over when palliative care begins when dealing with frailty in some patients.
- Some communities come from countries without palliative care so find the service a welcome and positive thing – they may not know it exists though and the communications issues are further complicated by language and needing someone or something to explain it to them so they can understand what is available and how to access it.
- Different groups can struggle to access palliative care services – it can be unclear if this is through the GP or social services and then where do different service providers fit within care services provided (e.g. district nurses).

Specific examples given by participants

- Participant experienced EOL care in last year. Their mother died at home (as she wished). The GP Service was good and correct equipment was delivered (e.g. hospital bed). However, it was extremely confusing who to phone/contact at different times, particularly out of hours. They knew the District Nurses would be attending the house but not always when. Following her mother dying and before a doctor had attended to certify, a team arrived (at 3am) to collect the equipment from the house. This was not due to an emergency but because it was a quiet time when they could get such equipment runs done. This displayed an awful lack of sensitivity.
- Participant currently cares for her father at home (where he wishes to stay as long as possible). He ended up being taken into hospital, where it took two days for them to contact her and enquire as to what medication he was on. She had to try and find out via GP and hospice advice line. Very distressing as she didn't know. He also wasn't eating at the hospital because his menu/diet was not appropriate. He didn't recognise what was served as food (and the hospital seemed unaware of its own specialist menu or why it existed, i.e. for patients like this). She ended up cooking three meals per day at home to then take into the hospital for him. She eventually forced his discharge to bring him back home so she could care for him better there. St Luke's provided very helpful information and a booklet (through Dementia Cares) helped her list out some key facts about her father's likes/dislikes/ daily schedule (e.g. what he will eat, when he wakes, when he goes to bed

etc.). Her biggest anxiety as a family carer is that they will be put her father into hospital again – she stated that she should see hospital as a safe place but it feels like the worst place possible – he'll go in and it will be like a black hole with her having no idea who will be caring for him and a complete information blackout. This places huge anxiety on carers and families.

- Participant lost their 97-year-old mother two years ago. She was originally admitted to hospital after a heart attack and had a pace maker fitted. Whilst at the hospital, the family received different information from different clinicians and eventually found out she was to be discharged home, even though she “couldn't lift a glass of water”. The family were informed that carers would be put in place to assist. After equipment was delivered to the home, her mother suffered organ failure and was instead kept in hospital (although her desire was to die at home). The family asked about hospice care and was told this would be no different to that provided in the hospital. In General, family wishes were not respected. She was kept on a general ward though she was eventually moved to a separate room (after 2 days of family requests). Whilst in the separate room, there were not enough staff to clean her, so her daughter had to do this herself. The way she died and was treated still hurts terribly three years later.

Further issues raised

- One participant noted that the area (NW London) has a very limited number of hospice beds for the 500000+ people it covers.
- Pembridge Palliative Care Unit – a participant asked what the plans were for Pembridge. The review team said that no decisions had been made but that if it's closure were to be part of the review then it would go to full public consultation.

Brent palliative care and end of life webinar Wednesday 15 June 2022

We would like to say thank you to everyone who attended the event. Their thoughts and feedback will be used as evidence as we move forward to develop the future model of care.

Key points/questions raised

Whether palliative care services are free of cost at the point of delivery – they are.

Do Palliative care services take into account ethnic background and the needs of Brent's diverse communities – the current review work is actively seeking to understand where the gaps are in terms of cultural and faith needs from palliative care and ensure services are culturally aware, sensitive and diverse and that there are no barriers to accessing them.

Lack of hospice facilities in the south of Brent and the difficulties in travelling to hospices further away – these considerations are very much part of the current review and we would encourage people to come forward and tell us more about their experiences as we seek to develop solutions as close to homes as possible.

Lack of clear information on the options available to people and linked to this the lack of fluency in English amongst some communities – the voluntary sector, with its existing strong links into different communities, have an important role to play here. Also the district nursing service, for example, have access to interpreters and interpreting services. We need to ensure these services are being utilised effectively. Information needs to be better shared with the voluntary sector so they are equipped to inform people. NW London has a programme focused on improving working with the voluntary sector and Brent is also improving the links between its service providers and the voluntary sector / outreach workers.

Accommodation and family situation – many in Brent live in one bedroom homes with no family and It’s unclear how these people are being addressed through the review. Whilst the review is considering how best to provide the services that people need, part of the challenge outlined is around how health and social care services work better together (e.g. through things like the Brent Health matters team) and another part (overcrowding and cramped accommodation) is a challenge beyond this reviews/the NHS’s remit.

Draft resource pack on palliative care services – this needs further work and in particular needs more on what can be done before the end of life to access services and equipment. It’s recognised as a good start but will need to be improved and kept up-to-date so it is accurate.

Communication between service providers and specialists was raised as an issue - particularly when the family/carer is dealing with a sudden downturn in the patients’ health and feels stuck in between services and conflicting advice. This point has come up during other engagement events and the final resource pack should make clear at all times who the point of contact should be for the family/carer.
Rapid response and provision of mutual aid – the pandemic and responses to it showed that support can be provided quickly if we ignore silos and sidestep red tape to focus on outcomes. We need to take note of this within the review.

Pain relief at home – pain management and the in-home service is actively being looked at through the review and through additional work in Brent. Particularly issues around administering stronger forms of pain relief in the home.

9 Interim engagement outcome report

During the involvement period, we arranged a number of events and webinars, attended external meetings and arranged numerous one on one interviews with local residents and representatives of the voluntary, community and faith sectors. This engagement will continue throughout the length of the review.

The table below detail the engagement activity that has taken place or is planned.

Event	Boroughs	Date	Link to meeting/ outcome
Hounslow Integrated Care Patient & Public Engagement (ICPPE) Committee	Hounslow	07 December 2021	Find out more
Public involvement event	NW London wide	13 December 2021	Find out more
NW London Joint Health and Overview Scrutiny Committee	NW London wide	14 December 2021	Find out more
Older people’s Engagement at the Pavilions Shopping Centre in Uxbridge	Hillingdon	28 January 2022	Find our more
BME Health Forum Director interview	Hammersmith & Fulham, Kensington & Chelsea and Westminster	08 February 2022	Find out more
SOBUS Community Lead interview	Hammersmith & Fulham	10 February 2022	Find our more
BME Stakeholder Event	Kensington & Chelsea	22 February 2022	Find our more

	and Westminster		
North Kensington Health Partners	Kensington & Chelsea	03 March 2022	Find out more
RBKC Adult Social Care and Health Select Committee	Royal Borough of Kensington and Chelsea	03 March 2022	Find out more
Trustee, Kosher Dementia UK	NW London wide	04 March 2022	Find out more
Public involvement event with a focus on ethnic minorities	Hounslow and Ealing	Thursday 10 March 2022	Find out more
Public involvement event with a focus on ethnic minorities	Westminster, Kensington & Chelsea, Hammersmith & Fulham	Tuesday 15 March 2022	Find out more
Hounslow and Ealing Integrated Care Partnership Engagement Event	Hounslow and Ealing	Thursday 17 March 2022	Find out more
Public involvement event with a focus on ethnic minorities	Brent, Harrow and Hillingdon	Thursday 17 March 2022	Find out more
Public involvement event feeding back what we have heard so far and actions we have taken as a result	NW London wide	Friday 18 March 2022	Find out more
Hammersmith and Fulham Integrated Care Partnership end of life meeting 08 March & 03 May 2022	Hammersmith & Fulham	08 March and 03 May 2022	Find out more

Hammersmith and Fulham Integrated Care Partnership Event	Hammersmith & Fulham	Wednesday 11 May 2022	**Find out more**
Harrow Palliative Care and End of Life Webinar	Harrow	Wednesday 11 May 2022	**Find out more**
Come and help us shape the end-of-life care in Brent	Brent	Wednesday 15 June 2022	**Find out more**

We have committed to transparent and meaningful engagement at every stage of the work

We also linked in with experts both locally and nationally in certain areas including learning disabilities and homelessness. Their advice led us to carry out two literature reviews which have been published and used as evidence in the review.

We received a large amount of feedback which we are responding to and some actions have already been addressed as a result. There are also areas we are currently developing and implementing, or propose to do so, in order to address the issues raised. Some local residents have been kind enough to share their stories so we could use them as case studies to illustrate the good experiences and the challenges that people face when using community-based specialist palliative care services, so that we can learn from their experiences.

In addition to these meetings, we developed a number of online surveys through which local residents and health and social care professionals could give their views. Open-ended questions were also included to give respondents the opportunity to express their opinions in their own words. We also received a number of written submissions which were responded to.

It is our expectation that engagement with local residents will continue as we move forward. All boroughs have had the opportunity to be involved in a webinar or complete a survey.

Further webinars are already planned or being planned for Kensington and Chelsea and Westminster. The output of the webinars will be used to support the final report and new model of care working group.

All the public feedback received will be used by our model of care working group, which will be responsible for designing, planning and mobilising the future model of care for adult community-based specialist palliative care.

Membership of this group will consist of local residents, clinicians and other palliative and end of life care stakeholders. The group will be asked to:

- agree a common specification / common core offer for community-based specialist palliative care
- develop a new model of care to deliver the specification / common core offer
- map out how this can be implemented in each borough.

The work will draw on the national service specification for adult palliative and end of life care, the previous NW London palliative care review programme work and qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement. We will also utilise activity trend data obtained through the programme's data working group and undertake further work looking at the structure of our services workforce.

The expected output is a set of core service standards, requirements and service functions that will need to be delivered across NW London. There will also be a number of additional localised requirements that the local Borough Based Partnerships will have responsibility for implementing these in view of their local context and population needs.

We will work with the Integrated Care Partnerships, local residents and stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If substantial service change is needed, we will then need to consider if a public consultation is needed.

We understand and share local residents' feedback that having good community-based specialist palliative care services is really important. In some cases, the feedback that has been provided has led us to make changes to services where possible and have plans to do some more of this via this review programme. This is detailed in an insight report where we also detail areas where we are not able to make changes.

We would like to reiterate our commitment to work collaboratively with our public, patients, clinicians and other system partners as we move forward to develop the future model of community-based specialist palliative care for adults, which includes consideration of current services and where the locations we need our services in

1.1 Key findings from the feedback received

As laid out in the Issues Paper, there are eight broad reasons why we need to improve the way we deliver our community-based specialist services to make sure everyone receives the same level of high-quality care, regardless of their circumstances.

We have carried out an analysis of all the feedback received through the webinars, surveys, one to one conversations, meetings attended and literature reviews and grouped the feedback received against the eight broad reasons.

1. **To review the valuable learning and feedback received from previous reviews of palliative and end-of-life care services carried out in Brent, Hammersmith and Fulham, Kensington and Chelsea, and Westminster, and the further engagement activity carried out in Ealing, Harrow, Hillingdon and Hounslow.**

In the previous review of community-based palliative care provision in in 2019 and 2020 we talked to people about community-based specialist palliative care services and heard what a crucial role the services play. The feedback confirmed that people value their local specialist services and would like to receive them as close to home as possible, and people with experience of these services are very positive about the care they have received. Local residents and stakeholders said they would like the NHS to reopen the Pembridge Palliative Care Unit in-patient beds following their temporary closure in October 2018 due to a lack of specialist care consultant cover and being unable to recruit due to the national shortage of trained personnel (see Section 1.2 Insight report and actions taken for further details).

We also heard that services need to be made available to more people 24 hours a day, availability of care needs to be improved during the out-of-hours periods (between 5pm and 9am) particularly, services need to be more inclusive and adaptable, offer more choice and more be more joined up. People told us it is important to improve access to these services so more people receive care and are supported to die in their preferred setting, whether this is at home, in a hospice, or in hospital. It is also important that people don't have to travel too far to access services.

The feedback showed that people have different views on how we should make these improvements. We want to build on the feedback and what we have learnt from it.

See the Palliative care services Independent review - full report Review of provision in Kensington & Chelsea, Hammersmith & Fulham and Westminster.

See the Palliative Care Services Public Engagement Report July 2020 In the boroughs of Brent, Hammersmith & Fulham, Kensington & Chelsea and Westminster.

In January 2020, Hillingdon Commissioning Group (HCCG) performed a review of End of Life Services looking at the views of general practitioners (GPs) and the lesbian, gay, bisexual, and transgender community (LGBT).

See the Review carried out on End of Life Services in Hillingdon in January 2020.

2. **To bring services in line with national policy. Such as**
    a. **the national Six Ambitions for Palliative and End of Life Car**
    b. **the NHS triple aim of improving access, quality and sustainability**
    c. **Ensure providers follow the National institute of Care and Excellence (NICE) guidelines for palliative and end-of-life care services.**

- We will utilise the learning and gaps in improvements taken from the borough and ICS level self-assessments against the six national ambitions for palliative and end of life care.
- Future community-based specialist palliative care services will need to align with national standards and guidelines.
- This includes adhering to the national service specification for community-based specialist palliative care.

3. **To meet patients’ changing needs arising from changes in the population.** ***By 2040, the number of deaths within England and Wales is expected to rise by 130,000 each year. More than half of the additional deaths will be people aged 85 or older, so there will be an increased need for palliative and end-of-life care services.***

- We will need to take into account aging population with likely increased demand on community-based specialist palliative care.
- The number of people living with dementia is increasing which brings increased complexity of care needs.
- The number of elderly people living on their own is increasing with no one to care for them. Often they can live away from their family leading to social isolation.
- This includes support for the family and carer supporting them.

4. **To reduce health inequalities and social exclusion, which act as a barrier to people receiving community-based specialist palliative care.**

- Review should look at ways of tackling the widening Health Inequalities for people who require palliative and end of life care and support service.
- Attention should be given to isolated people, those with family outside the country or in different regions, elderly couples that are physically or mentally unable to care for each other, the large number of disabled people that require specialist care and those who experience homelessness.

5. **To make sure that everyone receives the same level of care, regardless of where they live. At the moment there are differences in the quality and level of community-based specialist care services that patients, families and carers across North West London receive. This means that depending on where a patient lives, they and their family and carers may always be able to get the support they need, and may not be able to have their wishes supported at the end of their life. We want to do all we can to make sure this is not the case.**

- Implement a 24/7 telemedicine co-ordination, advice and support service for care home staff to better support their residents at end of life.
- To improve co-ordination and navigation of care and support available, implement a single point of access (preferably a single telephone line) for patients, family, carers and clinicians to contact to obtain information about what palliative and end of life care services are available, how to access them, support with getting medication and equipment etc.
- To build flexibility into the service model that supports a person and their family to change their mind about place of care and place of death even if it is at the last minute. This could be where a person has always said they wanted to die at home but change their mind as they and the family are scared or believe it is too hard on the family who initially thought they could cope. Instead they want to go to a hospice or a hospital.
- Align GPs more closely with individual care homes and develop enhanced care services.
- Pembridge in-patient service should be reopened.
- A review of the number of hospice inpatient beds should take place.

- The number of and quality of care plans need to be improved. Patients and families need to be given access. More needs to be done to ensure health professional access the care plan routinely when seeing patients.
- There needs to be improved record keeping around preferences, treatment etc. and more needs to be done to make sure they are automatically accessed by the people providing care.
- The need to identify that someone is dying and recognise this earlier was identified as an important point that feeds directly into the patient and families choices about appropriate treatment etc.
- We need to make sure that there are wrap around care to provide support to the patient if they are to stay at home.
- Care needs to be holistic, and include clinical and non-clinical support e.g. Home adaptations, advice and support on what to do when a patient passes away.
- There is a lack of bereavement support across NW London for families and carer. A review of current provision is needed to understand what type of support is needed and how it could be delivered.
- We need to ensure we consider the impact of caring for someone who is dying on family and carers. Concerns were raised about impact on:
    - unpaid carers and those who are older
    - Those who have their own health issues and are struggling
    - Are trying to hold down employment or have kids and are busy and what that means for them trying to undertake a caring role.
- The way someone dies can have a big impact on the person caring for them and we need to ensure that support for relatives and carers continues after the person has died.
- Palliative and end of life care needs to be patient centred and the importance of family/carers/those of importance to the person being involved in decision making and kept informed.
- We need to think about how we design more integrated services, between the patient and family, the community, social care and clinical services.
- Care and support needs to be available 24/7 365 days a year (including pain relief). out-of-hours service (OOH), consider including an OOH service to impatient services to enable carers and patient seek help when needed.
- Lack of clarity for carers/family around medication. Medication for EoLC patients should be thoroughly explained to carers/family members so they are able to identify which medications are missing and act quickly.
- Family members and carers should be kept informed at every point during a patient’s care pathway.
- Professionalism, Confidentiality and Compassion - Clinicians visiting family homes to see EoLC patients should be briefed fully on the patient’s condition/situation and maintain the highest level of confidentiality when they are communicating with other clinicians in the presence of the patient and other family members.

6. To make it easier for people to access services, particularly across our more diverse communities. Some of our services are not joined up and do not work well together, and we need to change this.

- More needs to be done to create culturally competent services that take into account cultural and faith beliefs.
- We need services that are able to care for people from ethnic minorities who may not speak or have difficulty speaking and understanding English.

- Participants identified a need for existing care and support services to do more in reach into different communities in a culturally sensitive way.
- More needs to be done to promote community-based specialist palliative care, encouraging people to think, talk and plan about end of life care.
- The importance of having local services was stressed with reference to the cost, time and difficulty of using public transport.
- Need to design services that take into account people cultural and faith needs.
- Creating seamless service provision with services properly integrated with other ancillary services like 111 would make them easier to access and improve patient experience of care.

7. **To cope with the increasing financial challenge, the NHS is facing and the effect this has on community-based specialist palliative care.**

- Consider a proper financial settlement for hospices as their financial situation has been exacerbated by Covid.
- Local residents wanted to know more factual information on finance, demography and the help available locally.
- Look at ways of clawing back some funding from the NHS service providers when patients with intensive clinical needs decide to die at home.

8. **To reduce the difficulty, we are having finding, recruiting and keeping suitably qualified staff, and the knock-on effect this has on our ability to provide services.**

- A comprehensive workforce plan is needed to address the workforce challenges mentioned in the report.
- More needs to be done to educate and train all workforce to identify need. This should be NHS, Local Authority (social care) and voluntary groups so they can capture and signpost potential need.
- Need to build extra capacity and extra staff to meet growing demand.

The full interim engagement outcome report is available here.

10 The model of care working group

The model of care working group was set up by the NW London ICS to develop a framework and action plan to ensure that high quality community based specialist palliative care is delivered equitably and sustainably across NW London, and that all residents are able to access the service if it is needed.

Membership of the group which meets on a weekly basis consists of local residents, clinicians and other palliative and end of life care stakeholders. Patient/carer members contribute and provide feedback on the group’s work, which reflects the voice of patients, carers and their families. They also work on projects which, have been identified as an area of focus by the membership group. Minutes of the meeting and presentations are available online.

This is not a plan to replace work that is already going on. It is a plan to build on the great stuff already happening and recognise where there are gaps and opportunities.

The work draw on the national service specification for adult palliative and end of life care, the previous NW London palliative care review programme work and qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement. We will also utilise activity trend data obtained through the programme’s data working group and undertake further work looking at the structure of our services workforce.

Objectives

- Agree a set of key ‘ingredient’ standards/ common core offer / single service specification for NW London
- Develop new model of care for community-based specialist palliative care
- Develop options for delivery of model of care
- Develop action plan for implementation

The expected output is a set of core service standards, requirements and service functions that will need to be delivered across NW London. There will also be a number of additional localised requirements that the local Borough Based Partnerships will have responsibility for implementing these in view of their local context and population needs.

We will work with the Integrated Care Partnerships, local residents and stakeholders to decide whether the new service standards can be delivered by existing service structures or whether a service change is needed. If substantial service change is needed, we will then need to consider if a public consultation is needed.

Who are the members of the model of care working group?

Members of the group included representatives from:

- NW London NHS community SPC providers
- NW London Hospice SPC providers
- Patients

- Primary Care
- Acute SPC
- Discharge teams
- Care homes
- Local Authority and social care
- Voluntary sector
- Meds management
- 111/OOH GP
- LAS
- Community nursing
- Continuing health care (CHC)
- Cancer programme

Model of Care – what do we mean?

There are many, many definitions of what constitutes a 'Model of Care'. We have set out below what we think the scope of this stage of work is:

Defining what the core elements of delivery are	Yes	This is the kind of detail within the national service specification and the starting point
Defining how much of these key elements we need	Yes	This isn't covered in the national spec but is critical to be able to ensure common approach across NW London how much" could include hours, staffing, capacity etc.
Defining how services should be delivered	Partially	For example, we may want to define elements such as access (including geographical availability) but not how services are integrated at place.
Who delivers elements	No	But substantial change not anticipated
How much costs	No	Not at this stage

The work will draw on the national specification for adult palliative and end of life care, the previous NW London palliative care review programme work, qualitative and quantitative feedback from residents and healthcare professionals obtained through our engagement and further data obtained through the programme's data working group.

11 Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026

In 2015 The National Palliative and End of Life Care Partnership published the **Ambitions for Palliative and End of Life Care: A national framework for local action (2015-2020)** to improve palliative and end of life care (PEoLC), building on the 2008 Strategy for End of Life Care and other strategies and reports.

It describes what is needed to realise that ambitions, and calls for local health and social care leaders to use these foundations and building blocks to collaboratively build the accessible, responsive, effective, and personal care needed, via a process that is open, transparent and effective.

A refresh of the Ambitions Framework (2021-2026) was published in May 2021, with a reminder that more must be done, building on the learning from COVID-19 pandemic to focus more efforts on personalised palliative and end of life care, to improve support for people of all ages including those bereaved, and to drive down health inequalities.

Each ambition includes a statement to describe the ambition in practice, primarily from the point of view of a person nearing the end of life. Each statement should also be read as our ambition for carers, families, those important to the dying person, and where appropriate for people who have been bereaved.

01 **Each person is seen as an individual**
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

02 **Each person gets fair access to care**
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

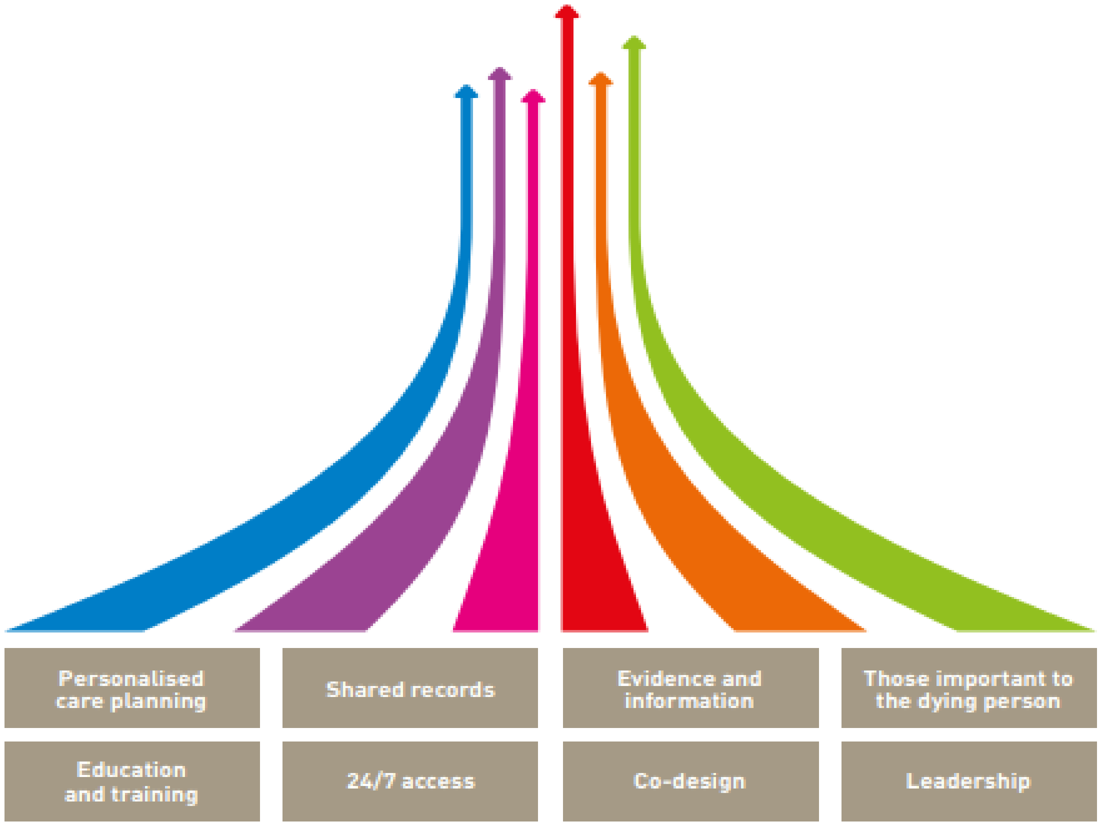
03 **Maximising comfort and wellbeing**
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

04 **Care is coordinated**
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

05 **All staff are prepared to care**
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

06 **Each community is prepared to help**
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

The eight foundations that underpin the ambitions and are required to bring about this improvement. Different individuals and organisations can lay these foundations, either on their own or collectively.



Foundations for the ambitions

To support delivery of the six ambitions, the NHS England & NHS Improvement Palliative and End of Life Care Team worked alongside stakeholders to further develop the Ambitions for Palliative and End of Life Care self-assessment tool as a national resource.

This tool provides a self-assessment framework and process to support localities/ boroughs to

- Support a more coordinated response for localities to determine their current level of delivery of services against the Ambitions for Palliative and End of Life Care - A National Framework for local action (2021-2026).
- To understand where there are strengths and opportunities for improvement and growth that need prioritising within future strategy for palliative and end of life care.

In order for this self-assessment process to become a meaningful and useful exercise, localities are encouraged to be as honest as possible, with cross-organisational collaboration to complete the tool and achieve the improvements being vital. Localities are strongly encouraged to ensure health and social care are equal partners in this assessment process.

All eight Borough Based Partnerships (BBP) were asked to complete the self-assessment tool and came together in two workshops facilitated by the NW London last phase of life programme to facilitate its completion. Participants included representatives of Brent Council and local residents.

All BBP’s have now completed the self-assessment tool. The rich discussions that took place in each BBP breakouts, and feedback from multiple workshop stakeholders, that completing the self-assessment tools with multiple stakeholders locally for each BBP was really beneficial:

- To ensure the information on the tool is as accurate as possible for each BBP and ultimately for completion of the NW London self-assessment.
- To raise the profile of PEoLC locally and regionally.
- To identify the relevant PEoLC stakeholders and building place-based links.
- To start the basis for driving PEoLC improvement work forward at place and within other programme areas.

An analysis has now taken place and a NW London level and this will be used to inform the new CSPC model of care (MOC) in development by the CSPC MOC working group. In addition:

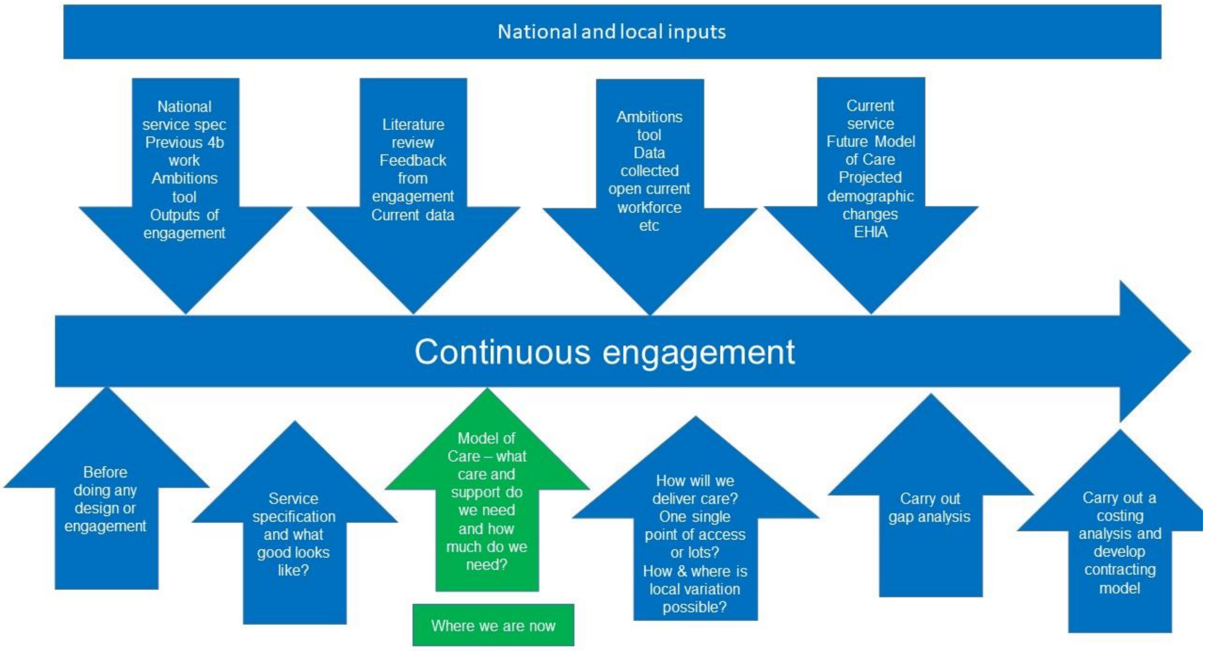
- Key gaps/ areas of improvement identified for other parts of the end of life pathway will be shared with other NW London programme areas.
- BBP self-assessments will be shared with BBP and borough directors with an ask to support any local PEoLC improvements using the findings to inform this work.
- NW London Last phase of life programme will host a 3rd workshop later in the year for all PEoLC stakeholders across the system to share the outcome of the NW London self-assessment, learning and areas of good practice identified.

We would like to thank partners and local residents for taking part in the workshops and contributing to their success.

12. Timeline

We are taking a flexible approach to the timeline to make sure that we can carry out good conversations with local residents and our partners within the Integrated Care System.

The diagram below shows the national and local inputs into the development of the model of care and immediate next steps.



It is anticipated that the model of care working group will complete its work in Autumn 2022. We will then move into a development phase where we will carry out a gap analysis, costing exercise and develop the costing model. This will be accompanied by the commencement of an assurance process with NHS England/NHS Improvement and the London Clinical Senate.

13 Conclusion

- We are undertaking a wide range of engagement and events to understand the improvements residents and health care professionals want in terms of community-based specialist palliative care.
- We have reviewed the feedback and published an interim engagement outcome report that is being used by the model of care working group which is responsible for designing, planning and mobilising the future model of care for adult community-based specialist palliative care.
- The inpatient unit at the Pembridge remains closed, however, we are currently providing alternative provision through neighbouring local hospices.
- We recognise that services need to be accessible locally and will review inpatient provision as a key part of the review, but cannot pre-empt what this means at present.

We welcome further feedback and suggestions from Brent Council. Please let us know by emailing nhsnwlccg.endoflife@nhs.net

Appendix 1 – Detail on the Palliative care services improvement programme in the London Boroughs of Brent, Hammersmith & Fulham, Kensington and Chelsea and Westminster. Note this review has been superseded by the current NW London wide process and as such the outcomes will feed in to that process but the options are not recommendations that we are actively progressing

In November 2018 Central London CCG, on behalf of West London CCG and Hammersmith & Fulham CCG, commissioned Penny Hansford, former Director of Nursing at St Christopher's Hospice, South East London; to independently review provision of community-based specialist palliative care services in the three boroughs following suspension of the in-patient unit at The Pembridge Hospice following that failure to recruit a consultant registered on the specialist register for palliative care which is required to cover inpatient care.

This event, combined with commissioner's desire to ensure palliative care services are fit for the future, meant the tri-borough CCGs decided to review the current provision of specialist palliative care. The independent review of palliative care services published with the aim of developing recommendations for an improved commissioning model that would deliver high quality services for patients, families and carers across the three boroughs.

A 'Call for Evidence' was launched on 14 December 2018 and a clinical steering group was created, with representatives from GPs, acute trusts, community trusts and hospice providers, all with an interest in specialist palliative care, with the final review published in June 2019.

The report provided a comprehensive assessment of the current local service provision, a review of best practice and made a number of recommendations for commissioners to consider for the future model of service.

Findings and future options

The review of services offered to patients identified the following three overarching challenges to be addressed:

- inequity of specialist palliative care services in the three boroughs
- inequity of access to the services, with only 48% of people who have an expected death having any contact with community palliative care services; and
- inequity of funding arrangements for the services from the CCGs.

The review put forwards three options in order to address these challenges whilst providing a sustainable local system, which ensures all patients receive care in their preferred place at the right time:

Option one (recommended option)

Tender a new community service with one lead provider for the specialist palliative care services, to provide an 8am-8pm co-ordination/case management centre. Out-patient, rehabilitation and well-being services should be easily accessible to patients and be located within the boroughs

Option two

Tender a new service and rationalise and reduce the number of specialist providers to two, with the same service specification and contracts and

Option three

Tender the services based on one community service per borough with the same service specification with one co-ordination centre/case management centre per borough.

Read the review in full here.

In Autumn 2019, the three CCGs were joined by Brent CCG as a commissioner of services at the Pembridge Hospice in holding a number of workshops to understand the experience of the end to end pathway.

Workshops were on held on ‘Access’, ‘Care’ and ‘Bereavement / aftercare’ with the purpose of having some in-depth conversations on the whole end to end pathway and use the information to feed into future potential scenarios for service delivery.

After listening to feedback from the public and stakeholders following the public workshops, we launched our ‘potential scenarios’ to the public for discussion and feedback and work in partnership with the public to design future potential options for service delivery.

This led to the development of four scenarios that set out how we might organise palliative care services in the future and in February 2020 we asked the public for their feedback on them.

Scenario 1—Services remain the same.

This scenario would keep all palliative care services as they are including the re-opening of the inpatient unit at the Pembridge, subject to the appointment of a palliative care consultant. In-patient, day and community care services would continue as they are.

Scenario 2- Some improvements to day and community services with in-patient services remaining the same.

This scenario would keep in-patient services as they are now, including the re-opening of the inpatient unit at the Pembridge subject to the appointment of a palliative care consultant.

Community services would also be standardised to 5 days’ week. This scenario would also lead to some improvements in the co-ordination of out of hours’ advice.

Scenario 3—A re-design of all elements of palliative care services.

This scenario would see in-patient services delivered from four rather than five sites but without reducing the number of beds that the NHS funds.

This would enable CCGs to fund enhanced community services 7 days a week, with 24/7 admissions for patients. It would also provide an out of-hours nurse visiting service and Hospice@Home available to all.

Scenario 4—A re-design of all elements of palliative care services including access to a new nurse-led inpatient service.

This scenario would see in-patient services delivered from four rather than five hospices but without reducing the number of beds that the NHS funds. CCGs would then fund enhanced community services.

Patients who do not have complex medical needs, but whose preference is to die in a hospice environment could receive nurse-led care at a bed in North Kensington provided by the Pembridge Palliative Care.

There followed a period of further engagement on the options with the public and a wide range of stakeholders which brought forward a number of themes and feedback on the scenarios.

- Dying in dignity and agreement on the importance of palliative care and local services
- Communication and awareness of death and dying, palliative care and the need to plan for it
- Capacity of service provision now and in the future
- Review process – residents wanted more information on the evidence being used to inform the process
- A strong desire to keep inpatient services at Pembridge and opposition to closure
- Agreement on the need to improve access to services
- Better and more clear engagement
- More information on the staffing issues
- More information on the finance issues
- To consider the impact of travel and transport when making decisions
- Recognition that there was a need for change

In summary we heard throughout the engagement period, that specialist palliative and end of life care services play a crucial role for people. The feedback confirmed that people really value their local specialist services and people with experience of these services are very positive about the care they have received.

We also heard that we could improve and that these services could be available to more people, be more inclusive, adaptable and offer more choice. The feed-back indicates however that there are differing views about how we make these improvements, and create a more equitable service for all.

View the full public engagement report

The decision was then taken to pause the programme of work due to the current coronavirus outbreak and the subsequent decision by the NW London ICS to look at community-based specialist palliative care services across the eight boroughs in NW London.