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

Community-based specialist palliative care improvement programme

Working together with residents, the Royal Borough of Kensington and Chelsea (RBKC) 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 the north of Kensington & Chelsea, whilst developing a new model of care that delivers a safe and clinically high standard service that meets the needs of patients at the same time and addresses inequalities across NW London.

The NW London ICS consists of all NHS organisations and local authorities in NW London who have been working informally as an integrated care system (ICS), ahead of legislation to put ICSs on a statutory footing. Legislation is expected during 2022, with the ICS becoming a legally recognised body later in the year. The following are partners in the NW London ICS.

- NW London CCG
- Central and North West London NHS Foundation Trust (CNWL)
- The Hillingdon Hospitals NHS Foundation Trust
- Central London Community Healthcare NHS Trust (CLCH)
- Hounslow and Richmond Community Healthcare NHS Trust
- Imperial College Healthcare NHS Trust
- Royal Brompton and Harefield Hospitals
- Chelsea and Westminster NHS Foundation Trust
- London North West University Healthcare NHS Trust (LNWH)
- West London NHS Trust
- Brent Council
- Harrow Council
- London Borough of Hounslow,
- Ealing Council
- Hammersmith & Fulham Council
- Hillingdon Council
- Royal Borough of Kensington & Chelsea
- Westminster City Council

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

- 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.
- The engagement period started on 18x November 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.
- The feedback we receive will then influence the subsequent development of the model of care that residents need. Its only when this has been done will we start to look at the what services are needed to deliver the model of care.
- 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.
- 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 RBKC and residents a focus on palliative care because of the importance of getting care and service provision right

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.

"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

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."

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.

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; and
- 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.

Whilst the eight issues above are relevant to all boroughs, in RBKC 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 many of these services were offered virtually. Where face to face outpatient appointments have been required (i.e. couldn't be carried out virtually) that would normally have come through day hospice, they have been accommodated at St Charles throughout the pandemic.

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.

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 services.

"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."

Bereaved story about 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.

We cannot resolve the current situation and issues unless we work in partnership with residents and other stakeholders –we welcome RBKC 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 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.

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.

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 recently embarked on a piece of work to ensure we reduce the chance of this happening working to the "You said, we did" approach."

This piece of work gives us some more structure to 'use' previous feedback to deliver change in the short term and means we can demonstrate to the public, patients and clinicians that we have valued and noted their views through the various points of engagement to date. In this work we are listing out what improvements we have already put in place, are currently developing/implementing or plan 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.

Below are a few examples of this work, which will be published on our NW London ICS website. Our aim is to continue to work collaboratively with our public, patients, clinicians and other important 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.

You said	We did
• 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	• 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

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.	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.
You said	**We are doing**
• Include clinicians in public engagement meetings and patients in programme working groups for the purpose of transparency and trust.	• During the four CCGs review of palliative care 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 are planning to have a clinical model 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.
You said	**We plan to do**
• Having hospice inpatient services locally is very important, particularly	• This programme will be reviewing the role specialist palliative care

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.	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 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.	• Bereavement care and support really came to the fore as a gap 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.

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

The current engagement period commenced on the 18 November 2021 when the NW London ICS published the Issues Paper and online survey and asked local residents and wider stakeholders including all partners within the NW London ICS to tell us what is important to you about adult community-based specialist palliative care.

We have updated the Community Based Specialist Palliative Care engagement plan based on what we have learnt from initial engagement sessions with stakeholders. The plan is split into the different stages required in terms of engagement.
Stage one, which is underway involves having conversations with colleagues and stakeholders covering different groups to help shape our engagement approach moving forward, revisiting the survey, assessing the data and undertaking regularly dissemination to new and existing contacts, through our ICP/ICS partners and other stakeholders.

On the 13 December 2021, the NW London ICS held a NW London wide engagement event with 40 people in attendance. We heard some powerful testimony from attendees and key learning from the event was:

- The number of elderly people living on their own is increasing with no one to care for them.
- The number of people living with dementia is increasing which brings increased complexity of care needs.

- 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.
- Whilst people often say they would like to die at home, they often change their mind and we need to make sure that services are flexible enough to accommodate this.
- We need to ensure we consider the impact of caring for someone who is dying on the day to day life of the person doing so.

We noted people asked for more notice, for digitally excluded to be considered and reported a level of frustration at not receiving feedback from previous engagements. We reafirmed our commitment to open and transparent engagement and have taken steps to ensure that all information is placed on the NW London ICS website.

On 14 December 2021, the NW London ICS attended the North West London Joint Health Overview and Scrutiny Committee (JHOSC) to brief members on the panel and answer any questions they have. We welcome the support given for the approach we are taking. Key questions and learning were:

- Concerns about health inequalities and how diverse communities can feed into this programme.
- Concern around future of the Pembridge in-patient beds so the residents have local access to beds again will be considered as part of the review, as well as importance of focussing on workforce.
- Questions about scope and why Children and hospital care not included.
- Need to ensure we look at what support is provided to people socially isolated/ people living alone or with families far away and dementia within the review.
- Need to ensure we take on board feedback given in previous engagement.

We will report back to the JHOSC following completion of the engagement period.

In December 2022, the rise of the Omicron variant meant that a number of our staff had to be redirected to support vaccination (and some work on Long Covid too) and disappointingly we had to pause the really productive conversations we had started. These have restarted and we have taken the decision to extend the engagement period until the middle of March 2022, when the pre-election period for the May local elections start.

An updated engagement programme has been developed based on what we have learnt from initial engagement sessions with stakeholders and conversations with a range of stakeholders including St Mungo's and the Advocacy Project relating to our homeless and learning disability populations.

The key piece of feedback from these stakeholders has been that that a lot of research has already been carried out with the homeless and learning disability communities and there is limited benefit in repeating this. Instead, we have been advised to review the previous research that has been carried out on this subject area and use this to shape what a best practice service offer for these communities could and should look like. The next stage would be to test this back with the professionals who support

these communities and then the communities themselves to ensure we have got it right.

We are also working in partnership with the eight borough based Integrated Care Partnerships (ICP) to design local engagement opportunities. This may be webinar/event based or take some other form depending on the requirements of the ICP.

Further engagement opportunities will be organised in collaboration with the voluntary sector London's ICP engagement teams and the NW London organisations and supported by NW programme team.

We will also be holding two ICS wide workshops to undertake a self-assessment for our ICS against the 6 National Ambitions for Palliative and End of life Care so we can access our current areas of strength and identify areas for growth that need prioritising within future strategy for Palliative and end of life care. These workshops will have clinical, operational and patient and public involvement.

The tables below detail further engagement activity that has taken place or is planned.

Type of event	Boroughs	Date
Ambitions Workshop 1	NW London wide	Thursday 3 March 2022 9.30am to 12.30pm
Ambitions Workshop 2	NW London wide	May 2022

Type of event	Boroughs	Date
Engagement team: small-scale interviews with community leaders	Westminster and K&C	Tuesday 8 February 2022 Completed
	H&F	Tuesday 8 February 2022 Completed
	Westminster	Wednesday 16 February 2022 Completed
	Tri-borough	Tuesday 22 February 2022
	Brent, Harrow & Hillingdon	Friday 25 February 2022

Type of event	Group	Date
Engagement team gathering feedback from conversations	LGBTQ+	Ongoing
Assess if further support required	Mental health	Ongoing
As above	Disabilities	Ongoing
As above	Homeless	Ongoing

Type of event	Boroughs	Date

As above	Westminster, K&C and H&F	Tuesday 15 March 2022 6:30 to 8pm
As above	Brent, Harrow & Hillingdon	Thursday 17 March 2022 6:30 to 8pm

Type of event	Boroughs	Date
Final full panel webinar	NW London wide	Friday 18 March 2022 9.30 to 11.30am

It is expected that following each event we will write a brief report highlighting the main findings and feedback which will then be made publically available on the NW London ICS website.

We would welcome further ideas and suggestions on how we could engage further. Please get in touch by emailing nhsnwlccg.endoflife@nhs.net. We want to be as inclusive and open as possible and appreciate any support in doing this work.

Draft revised programme timeline 2021 – 2023

To come to a conclusion that addresses the issues listed above and is sustainable in terms of workforce will take some time. A revised programme timeline has been developed that takes into account the stages of work needed including sufficient time for meaningful co-design and engagement. We want to conclude this work as quickly as possible but also ensure an implementable plan and have included in the timetable for figurative purposes the stages we would need to take if significant service change was proposed and we need to consult formally. The timetable will be revised if that does not need to happen,

Dates	Activity
18 November 2021 to 18 March 2022	Publication of Issues Paper and engagement
May 2022	Publication of engagement outcome report with confirmation of next steps
May to July 2022	Working through Clinical Model Working Group plus further external engagement – development of Clinical and Service Model.
July to September 2022	Engagement on options
August to November 2022	Development of options, EHIA and pre-consultation business case
August to November 2022	NHS England assurance processes including NHS England Clinical Senate and NHS England regional assurance process
October to November 2022	Sign off of pre-consultation business case by Integrated Care Board
October to November 2022	Prepare consultation materials

December 2022 to February/March 2022	Public consultation (12 to 14 week)
March/April 2023	Development of decision making business case
April/May 2023	Decision making business case goes to Integrated Care Board for decision
May/June 2023	Implementation process begins

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 specialist palliative care.
- We are reviewing previous feedback and existing research and building this in to the review.
- 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.

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.