



**North West London
Integrated Care System**

Working together for better health and care

Community-based specialist palliative care improvement programme

Report to: LBHF Health, Inclusion and Social Care Policy and Accountability Committee

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

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1. Introduction

Working together with residents, the London Borough of Hammersmith & Fulham 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.

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 Hammersmith & Fulham specifically:

- The co-production and engagement taking place at a local Hammersmith & Fulham level through the auspices of the Hammersmith & Fulham Health & Care Partnership (HCP) – see page 14
- Details on the area we know to be of most ongoing concern – and our efforts to address this – see page 10

We will continue to engage with Hammersmith & Fulham residents, stakeholders and teams to ensure the outputs of this review work for Hammersmith & Fulham, 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 Hammersmith & Fulham 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 Westminster, Kensington & Chelsea, Hammersmith & Fulham event that took place on the 15 March 2022 and the Hammersmith & Fulham engagement event that took place on 11 May 2022.
- In order to ensure effective local engagement; the Hammersmith & Fulham Health and Care Partnership (H&F HCP) worked closely with lay partners and members of Hammersmith and Fulham Save our NHS (HAFSON) to develop a local engagement strategy.

- Locally, it was agreed to extend the scope of the engagement to include the breadth of “out of hospital” Palliative Care Services within H&F (generalist and Specialist Palliative Care together). The feedback gained will feed into local service development as well as the NW London programme.
- HAFSON provided a welcome submission at a NW London level and we include this and our response published on the NWL ICS Website at www.nwlondonics.nhs.uk/get-involved/cspc/how-get-involved/interim-engagement-outcome-report-key-finding
- There are some things that we have found that needed to be addressed immediately. We found 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.
- 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 already 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. A short video was produced to accompany the launch and a newsletter that has been distributed widely.
- All the public feedback received is currently being used by our model of care working group, which is responsible for designing, planning and recommending options for the future model of care for adult community-based specialist palliative care to the Steering group.
- Membership of this group consists of local residents, clinicians and other palliative and end of life care stakeholders. The group has been 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 4 CCGs 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 in the absence of SPC consultant cover. 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 as usual.

We share with Hammersmith & Fulham 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

“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

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.

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 NW London. In NW 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.

3. Building on feedback from previous engagement

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.

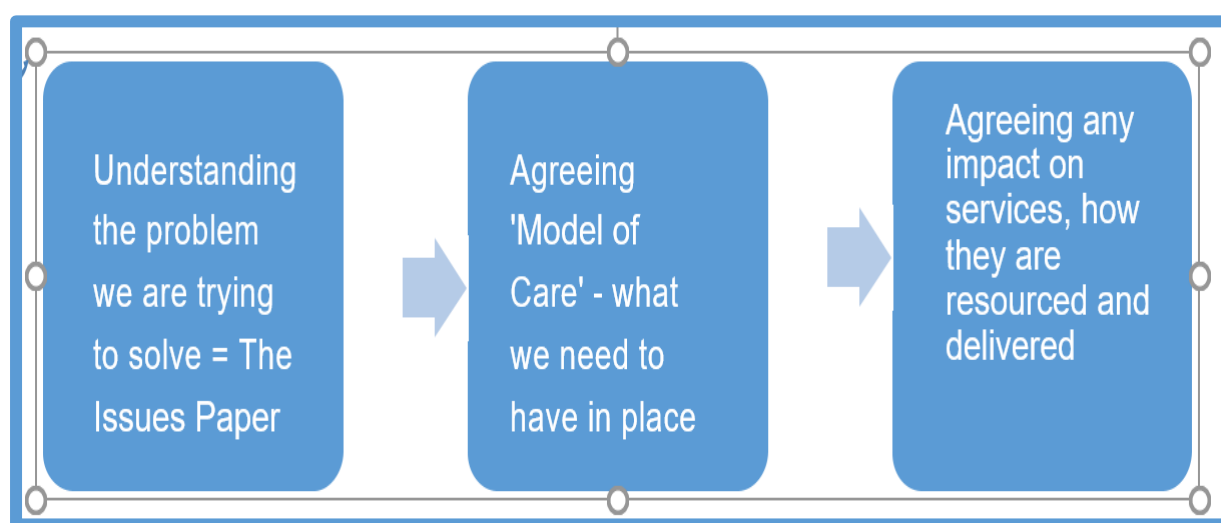
The feedback showed that people have different views on how we should make these improvements. We want to build on the feedback and what we have learnt from it. We also want to fully understand the role culture and religion can play in influencing the way people relate to their health, the support they 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.

For more information on the Palliative care services improvement programme in the London Boroughs of Brent, Hammersmith & Fulham, Kensington and Chelsea and Westminster, visit www.nwlondonics.nhs.uk/get-involved/cspc/how-get-involved/building-feedback-previous-engagement

4. Next steps

We cannot resolve the current situation and issues unless we work in partnership with residents and other stakeholders –we welcome Hammersmith & Fulham Council 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 provision 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 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.

5. 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
<ul style="list-style-type: none">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.	<ul style="list-style-type: none">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.
<ul style="list-style-type: none">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.	<ul style="list-style-type: none">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
<ul style="list-style-type: none"> Include clinicians in public engagement meetings and patients in programme working groups for the purpose of transparency and trust. 	<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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
<ul style="list-style-type: none"> 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. 	<ul style="list-style-type: none"> 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.
<ul style="list-style-type: none"> Not enough support available or consistent offer of bereavement 	<ul style="list-style-type: none"> Bereavement care and support really came to the fore as a gap nationally, regionally

support (pre and post death) available to patients, families and carers. Could this be reviewed as part of the latest programme of work to understand current provision and what more could be done to improve this offer.	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
<ul style="list-style-type: none"> We have heard from local residents and stakeholders that they would like the NHS to reopen the Pembridge Palliative Care Unit in-patient beds. 	<ul style="list-style-type: none"> 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 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.

	<ul style="list-style-type: none"> • 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. • For more details visit www.nwlondonics.nhs.uk/get-involved/cspc/how-get-involved/pembridge-palliative-care-service
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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.](#)

6. Hammersmith and Fulham Health and Care Partnership (HCP) Local Engagement Update

H&F Engagement Planning/ Strategy

In H&F, as part of the HCP, we have made a commitment that coproduction is at the heart of everything we do. Our aim is to work with the residents and communities from the very start, to understand what matters to them, to redesign services in a way that works for them, and to work with them to make changes. In order to ensure an effective engagement; the H&F team worked closely with the lay partners and members of HAFSON to develop the engagement strategy. We worked together:

- To design the engagement material, agree the narrative for a rich conversation,
- looked at ways to promote our event via voluntary sector organisations, tapping into their network to ensure we reach out to all the cohorts and everyone intending to share their feedback has a platform to do so e.g. via online surveys, written feedback via email or post to the NWL ICS team and virtual engagement events.
- To facilitate the conversation at the public engagement event.

H&F Engagement Scope

We wanted to engage meaningfully on the issues that affect people at the end of life and recognised it is difficult to separate out Specialist Palliative Care and general palliative / end of life care, therefore we decided with all the HCP partners in agreement to extend the scope of our engagement to include the breadth of “out of hospital” Palliative Care Services within H&F (generalist and Specialist Palliative Care together).

Event Promotion

We wanted to ensure the engagement options (Event and surveys) become visible throughout the Hammersmith and Fulham for all the communities and cohorts therefore we reached out to all our partners, a number of charities and voluntary sector organisations to promote our event.

- Colleagues from HAFSON (Marion Summerfield, Merril Hammer and James Grearly) have been instrumental throughout the engagement process and key in promoting our engagement event and online surveys. They advertised the event on HAFSON website and promoted the link to their network members.
- Initial findings from the ICS work revealed that the Ethnic minorities, LGBTQ+ and faith groups were not using the service as much so we linked in with BAME Health forum and Opening Doors London to tap into their network to spread the word and encourage residents to come share their views with us. BME Health forum published our event details on their website, included it in their newsletter and also sent it to their network individually. Opening Doors London promoted our event on twitter and Facebook.
- SOBUS published the H&F event on their website and promoted it via their April and May newsletter. Sharon Tomlin from SOBUS has offered to help us arrange individual engagement sessions with specific communities and faith groups in phase 2 of the engagement.

- Providers of Older Peoples services (POPS) forum - It is an initiative to get the voluntary sector in Hammersmith and Fulham working in collaboration with older people's issues. The Borough team presented at the forum 19 April 22 and requested all providers to promote our event and surveys. This forum was attended by over 30 provider organisations.
- Older Peoples Care Homes and DOM care providers within H&F circulated the survey link and event details to their existing and previous clients.
- Local authority team advertised the event through their social media channels.
- The event details were shared with the Patients / Citizens Panel that have over 220 members signed up for H&F.
- In addition to the above following organisations promoted the event via their website, newsletters and social media handles e.g. twitter, Facebook, Instagram etc.
 - Carers Network
 - Healthwatch Hammersmith & Fulham
 - Imperial Warf Resource centre
 - White City Community e-newsletter
 - Royal Trinity Hospice
- The HCP team linked in with various other forums and voluntary sector organisations / charities including: Age UK, H&F Community champions, Maggie's, Marie Curie, H&F Disability Forum etc. to promote the event.

H&F Engagement

Virtual Event & Meetings:

- Engagement via End of Life HCP subgroup meeting held on 8 March 22
- Engagement via End of Life HCP subgroup meeting held on 3 May 22
- Hammersmith and Fulham Health & Care Partnership Public Involvement Event held on 11 May 22

Questions we asked at the engagement event

H&F has a diverse population and it important for us to understand our communities' views on death and dying.

- What is good about Palliative and End of life Care in our area? What is working well for our residents at the moment?
- What needs improving?
- What does "good death" mean for our communities considering their cultural, religious and ethnic background?
- What do we need to consider and change about palliative and end of life care services to make it more equitable and accessible for our diverse population?
- If there is one thing you would change, what would that be?

Other feedback Options

Online Surveys

- Long survey for those with experience of community-based specialist palliative care - [Community-based specialist palliative care - full survey \(jotform.com\)](https://www.jotform.com/survey/community-based-specialist-palliative-care)

- A short online survey for those with no experience of community based specialist palliative care.- <https://form.jotform.com/213391249977367>
- Small-scale survey, by clicking on this link - <https://form.jotform.com/220603723913348>

Feedback in writing

- Via Email to nhsnwlccg.endoflife@nhs.net
- Via post to: Community-based specialist palliative care review, North West London Clinical Commissioning Group , Ferguson House, 15 Marylebone Road, London NW1 5JD

H&F Health & Care Partnership (HCP) Engagement Outcomes / Feedback

Key Highlights from the Public engagement event held on 11 May 22:

- **Support for patients with addiction, isolation, loneliness and vulnerability** - A question was raised on how to refer vulnerable patients to palliative care who have addiction and live in Isolation. An example given of a man in mid 40s who had alcohol addiction, his GP was aware of the addiction and supporting the gentleman. However, the concern raised was how people like this have access to EOL services. There is evidence that people with addiction and loneliness have shorter life span therefore Palliative care needs to consider everybody regardless of their circumstances or location. ***We need to use the borough partnership to find effective way to link between primary care and primary care network and the services available in the borough to support those in isolation and enable them to get the support they need.***
- **Saving Pembridge Hospice** – Questions were raised on why the Hospice inpatient unit is still closed? Care needs to be delivered closer to home especially for patients in last days of their life. It is a vital part of the offer to the local people, particularly those who don't have any family to rely on. The ICS was asked to consider seriously bring it back into use as it is a very good example of what can be done to help people have a good death. Due to closure of these beds, patients and their families, carers have to travel further for EOL service which is not ideal. We need to consider making resources available locally. Nearly 2000 signatures have been collected to save the hospice and these will be sent to the ICS Programme team via email to nhsnwlccg.endoflife@nhs.net
- **Simplify documentation** – A call was made for Palliative care consultation documentation to be made simple and easy to read for local communities. The current materials need to be put in non-jargonistic terms.
- **Out of hours' access to nurses and care** should also be considered as there is limited or no support available in some areas in evenings, nights and weekends. We heard an example of a patient receiving care at Royal Marsden Hospital who was continuously unwell. It was difficult to get access to a Macmillan nurse after 5pm and

this lack of support when it was needed was very stressful for the carer and patient, who understandably wanted to avoid A&E at all costs as not an ideal environment for someone on chemotherapy.

- **Patient's choice matter** – a patient's story was shared. He was told he had days to live, he was not able to communicate well and without an informed discussion with him or family, he was suddenly moved to a care home where the wife could not visit. Patient died alone in a care home and the wife is now suffering the effects of this. about this. We need to improve the system to ensure everyone gets to choose and care is delivered at the chosen point of delivery on time without delays. This is another example showing Pembridge being closed have an impact on local people.
- **Concerns about separating specialist palliative care from totality of palliative care support** – we need to ensure a holistic picture is considered as part of the review. **Continuity of care between places and forms of care is vital** and when it breaks down it creates problems – the value of hospital, hospice, District Nurses and GPs are important to the patients in all this and must be considered together. - *We will do this by connecting the work in the boroughs with local teams and the work of the NWL team working on the Community Specialist Palliative Care review, alongside other NWL teams working on other parts of the system.*
- **Flexibility is important** - patients and their carers need to know that the patient can be moved between places of care, between caring agents as needs change and it needs to happen quickly without delays. It should include assessment of needs, rehabilitation, respite as well as ongoing care.
- **ParaDoc Model of Care** – A suggestion was made to introduce ParaDoc model of care in H&F. This is working very well for communities in Hackney especially for patients with hospice at home. The team comprises of a Paramedic and a Nurse in a car. They have support from the GP where required and have access to summary care records. Rather than taking the patient to A&E, they can carry out advanced assessment, prescribe medication, stabilise the patient at home. They carry treatment equipment along with a range of oral and injectable drugs, including End of life drugs. This was a good example of new developments to support people to remain in the community.
- **Access to relevant Information is critical** – we need to ensure that people who are caring for somebody have access to the record and the patient notes.
- **Equitable Care provision** – We need to consider equity in care provision. Improvement is needed in the current core services. Care plans should be based on patient's needs (clinical and social).
- **Improve integration between NHS service & Council Service** – concerns were raised whether palliative care is joined up with the social care delivered by the local authority. A member shared their experience where her mum had 2 carers coming four times a day. Frequent change between carers did not work and was very unsettling, however the palliative care provided by the district nurses was excellent during working hours and out of hours. On three occasions, social carers called for an ambulance instead of having a discussion with the family. On one occasion, the district

nurse had to visit to talk to the ambulance crew, she explained them that the patient was dying and did not want to be moved to the hospital. The crew agreed and left. The patient died peacefully after three days. After the death, District nurses remained in contact with the daughter to support her and came back to remove the catheter. Patient's family felt supported through the NHS side but believe that the linkage between NHS service, Council service and voluntary service should be looked at. It needs better integration.

- **Guidance and training for Social Carers** - A member shared their experience and mentioned she had an excellent support from District Nurses and GP. She felt very supported but suggested that guidance and training for social carers on how to make the last days of a person's life palatable/comfortable would be helpful.
- **Death Café / Coffin Club** – a suggestion was made to explore having Death Café / Coffin Club in H&F. A charity organisation currently runs this service in a neighbouring borough. They have social gathering about beginning conversations about death, looking at death in a creative way and normalising the conversation.
- **Spiritual support in EOL and education to facilitate this-** Spiritual support / service is important for many ethnic minority communities. Training not only from the perspective of the patient whose life could be coming to an end soon but also for spiritual leaders so they have a better understanding of palliative care is important. Some faith leaders are actively involved and very aware however some are not because they are busy and stretched, supporting their congregation and their members. It was suggested that education and raising awareness amongst various communities would be very helpful.
- **Inequalities in accessing services** - We need to consider Inequalities in accessing palliative and end of life care for people from different ethnic backgrounds. Having regular death cafes will help raise awareness. We need to continue the engagement to identify inequalities. Sharon Tomlin from SOBUS mentioned there are different ways to engage with communities and offered to help with targeted listening around palliative care.
- **Assessment tools in borough** – A question was asked about how we take note of what the Community says about their extensive experience about life and death and the palliative care service generally? How is the feedback documented and how is it assessed? How is it fed up the chain within the system to create meaningful listening and dialogue?
Response – Today's conversation is an example of meaningful listening, our team has tried to reach out far and wide to ensure we hear from our local residents from all communities. All the feedback gathered for Specialist Palliative care will be submitted to the ICS programme team to inform the current review. One of our Campaign groups in our borough based partnership has a subgroup focussed on End of Life – this is an on-going piece of work and all the general palliative care related feedback from this event will be submitted to that group to help them shape their work and agree priorities. In terms of keeping this conversation going and getting input from our communities we are open to any ideas this group can share.

- **Reducing Unnecessary Hospital admissions in EOL** - Concerns were raised regarding the figures included in the presentation i.e. 49% died in hospital and the need to reduce this further. A member questioned how would this be achieved especially with the new bill it is going to be even more problematic. The view was that most of these people died in hospital because there was no alternative place such as a hospice or a care facility or the social workers could not sort care for them at home.
Response - In response to this the Chair stated that we don't have an immediate answer to that at the moment but the intention is to design a system that tackles this issue. The ask for tonight is to feed views into the NWL system so that we can design a model of care for the future. The development of new model starts in mid-May and completes in end of August. The aim is to design something that is going to provide good quality care and equity of access and choice and all the things we've talked about in terms of being really important.
- **Equivalent Support for people who do not associate with spirituality or religion**
– A view was expressed that we need to consider at what point do you start a conversation with them and at what point would you start to introduce the Death Café, Coffin club? Many people have different ideologies around death and we need to be mindful that not everyone would need / prefers spiritual support.
- **Role of carers and how they are supported** – A lot of carers are unpaid volunteers from voluntary sector or are family members and a lot of burden is often put on them. It is important to consider what is asked of carers and to think carefully how they are supported by the system. It was felt that carers are on the whole not recognised well by the system and need more support.
- **Helpline/ Single point for contact** – strong views were expressed around the need for the EOL patient and their family/ carer having a single person or a single team identified at all times that they can contact for advice and support. People need assurance that there will be somebody, a name person or a team easily contactable when needed and that decisions related to the patient's care will be made on time without any delay.
- **Consider Gender issue** – a point was raised regarding the gender of carers, and the impact on women carers as also there is an increasing number of women living alone in H&F and in NWL. It has a real implication for what care might, could, should be provided at end of life.
- **Promote information and understanding of available services for local residents**
– a simple and easy to read format for older population and people with Mental health conditions should be made available and readily distributed. This will help create awareness on what is available and who to call on when needed.
- **Continuity of care for people with Dementia** – changing carers often and seeing a different carer frequently is not appropriate for people with dementia- it causes confusion and is difficult to cope with. We need to lobby for longer carer calls than 15 minutes for people with dementia at that stage of life. Patients' needs should be properly considered.

- **Religious & Spiritual support for BAME population** –feedback was shared from previous engagement with BAME residents outlining Islamic, non-Islamic and Jewish communities who said they prefer dying at home rather than in a hospital. They would like religious / faith leader or regular Muslim clerk or Imam be available in last days of life. There should be an emphasis on the need to build cultural awareness in the services.
- **Break Language Barrier** – Views were raised around language support for non-English speaking residents to be considered at each stage in care provision. Information should be made available in people's preferred language, and interpreters should be made available at appointments or wherever required.
- **Dignity, Choice, Personalised Care** – there was an ask to consider patients' needs. If for example someone wants someone religious, it needs to be someone they can relate to and not some appointed standard personnel. Dignity and choices is most important and it needs to be personalized.
- **Quality and Consistent Care Closer to home** – there was a strong view that care facilities need to be close to home as it is vital for both patient, their family and carers. Hospices at one point played a hugely valued role but are less available than previously. A lot of families would love to have the choice of hospice care as they don't want their loved one to be in a hospital. There needs to be a consistency and transparency in services. We need to consider how we create consistency? How we make sure everyone has an equitable offer based on their needs regardless of postcode.
- **Make Palliative care accessible for people** – views were expressed that there's no point having an amazing specialist palliative care services if we don't have the palliative care accessible for the majority of people in the community. It needs to start with the primary care services. The primary care services starting from the GPs and district nurses are critical to leading the palliative care provision and to recognize when someone is reaching the end of life and to be able to provide the basic care to them because it will be the very few that will need the specialist palliative care provisions i.e. hospice provision. We have been living with death and dying for thousands of years without the existence of specialist palliative care. So now we are very fortunate that the specialist palliative care exists, but it's not necessary for the vast majority of people. If we have primary care services that can reach people where they live and if we have GP's that can go out and meet people in their own home, we will avoid a lot of unnecessary hospital admissions at the end of life. A member highlighted that we may not be using the specialist palliative care service the best way we could e.g. we are not using Royal Trinity Hospice at 100% of its capacity as it has 28 beds and a part of the hospice was closed during COVID. It caters for H&F and K&C so we need to consider if we really need to have two inpatient units for H&F (i.e. Royal Trinity and Pembridge)? From a practical and financial prospective, it is very expensive e.g. the palliative care provision in a Hospice bed that can be around £500 per day, while with someone at home, it may be cost about £100 or £150 a day. Key is to invest more in general palliative care and have the GP's/primary care services and district nurses leading on the palliative care provision.

- **Empower Family and Carers to handle medication-** Views were expressed that we should consider experience from other countries. It doesn't need to be only a healthcare professional to give essential end of life medication to the patient at home. We can train relatives to give medication including injectable medication. This is happening in other countries and it saves a lot of distress for patient as they don't need to wait for a nurse to come and give injection. It also helps the relatives/ carers to have a sense that they are helping that person to live better until they die.
- **Care Homes as potential resource to support with EOL care** – consider having gold standard care homes specialised in the provision of palliative care and end of life care for residents.
- **Support for Family and Careers** - a question was asked about what happens after death and consider how we should support the relatives and carer of the deceased patient. Psychological support, access to bereavement service is very important.
- **Choice of dignified death at a chosen place** – Patient's choice is important and should be at the centre of care. A care/ nursing home is still very clinical. It is almost like a hospital and are often understaffed. It's equivalent of a hospital because people don't have a choice. Sometimes people go to a care home because they can't get into hospital. It is appropriate for some people, but it should not be a decision that's made for people without their choice. There are not enough hospices around and we need more hospices as it gives patients the feeling of cosiness, homeliness, warm personalised space/ environment that may be lacking if one cannot be in their own home. Hospices provide music therapy and all sorts of support and therapies to create a good death.
- **Integrate knowledge sources**– it was thought that our system is complex and not joined up with acute hospital, GPs, Care homes, Hospices. The challenge for the public and all partners is what our current infrastructure looks like and how we bring the good work together so it is understandable and integrated.

One thing you would like to change?

The following points were made

- **Information hub / Recognised system** – We need to build a recognised system i.e. a point of contact an identifiable team of people which is known to public (not just the doctors) that people can contact for advice or to get information on what services /support is available for them and what choices they have. We need a point of contact in our borough where people can contact when they think they need. Within that it is important that people feel they have actually got a choice and perhaps not every choice can be met but the option of having an informed choice and not being forced into making a choice that is good for the NHS because it is under pressure. We need to provide **assurance that people have a choice which is going to be listened to and respected and as much possible met.** It is important to have a choices recognised by system and to have the flexibility to change your mind if needed.

- **Consider what is it about the hospice that we need to create in other settings** and how we foster that? how we make this available outside hospice and in community?
- **Remain updated** - staff should be aware and be educated about the changes happening within the system.
- **All the GPs & nurses need to feel confident about palliative care** as they are the ones that are more in close contact with the patients and can give them options in terms of the care according to the people's wishes and preferences, they can make it happen and then all the other services would need to work around it to ensure people can die where they want to die.

Key Highlights from EOL meeting 8th March 22 & 3 May 22

- **Service Awareness and Effective Triage** - We need to ensure the service is cohesive and delivered in a connected way. Sufficient information on what is available within the system should be available for healthcare professionals, carers and service users to ensure timely and effective triage.
- **Proactive Approach instead of reactive** - It is important to have a discussion prior to a crisis to record patient's choice i.e. finding out where the patient would like to spend their last days of life e.g. home, Hospital, hospice, Care home etc. and encouraging them to make decisions.
- **Improve GPs awareness** of end of life services and support from the hospices.
- **Improve communication** between primary care, secondary care, social care and district nurses in terms of seamless discharges whatever day of the week which make things happened quickly and enables people's wishes to be carried out.
- **Ease of access, awareness, peoples wishes to be at the centre** – Patient's choice is important and should be at the centre of care. Early communication between district nurses, patients and family members is required especially when patient's choice and families' wishes don't match as this can creates conflict and negative experience in the end of life care.
- **Include patient, family & Carer** in the early stages of care planning and communication.
- **Family and Carers** – Support the carer who is on that journey – think about how do we navigate the carer's needs, what support is available for them in the system and how we can raise awareness on what is available? – signposting is important.
- **Staff Awareness** - Support the staff in improving their understanding of Carer's psychological impact of losing someone, through stories i.e. patient, family and carer stories.

- The group suggested a small scale pilot – a leaflet outlining first point of contact and available services – look at what services are available within the borough and create a single point of information leaflet outlining these for patients, family members and carers.

Next Steps

- All the feedback collated on Specialist Palliative care has been reported to the NWL ICS Programme team to support the NWL wide review of CSPP services. It will be used by the model of care working group 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. H&F Lay partners and members from HAFSON are active members of this working group.
- Overall engagement feedback including General Palliative care has been reported to the “End of Life Subgroup” under Frailty campaign of the H&F HCP. This working group will utilise the engagement feedback to identify areas for improvement and agree priorities for delivery on a borough level. This group has representation from Carers Network, Lay partners, HAFSON, acute providers, community providers, district nursing teams, community response and enablement team, Local authority and CCG.
- H&F HCP team will continue to support the NWL ICS programme team with further engagement and delivery throughout the review.
- We will continue to work collaboratively with all our partners, communities and residents to co-produce change.

7. 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 and Westminster	22 February 2022	Find our more
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

Event	Boroughs	Date	Link to Meeting / Outcome
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 borough based health & 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

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 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 Care**
 - 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.
- Pembroke 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 carers. 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 inpatient 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.](#)

8. 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.

9. 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.

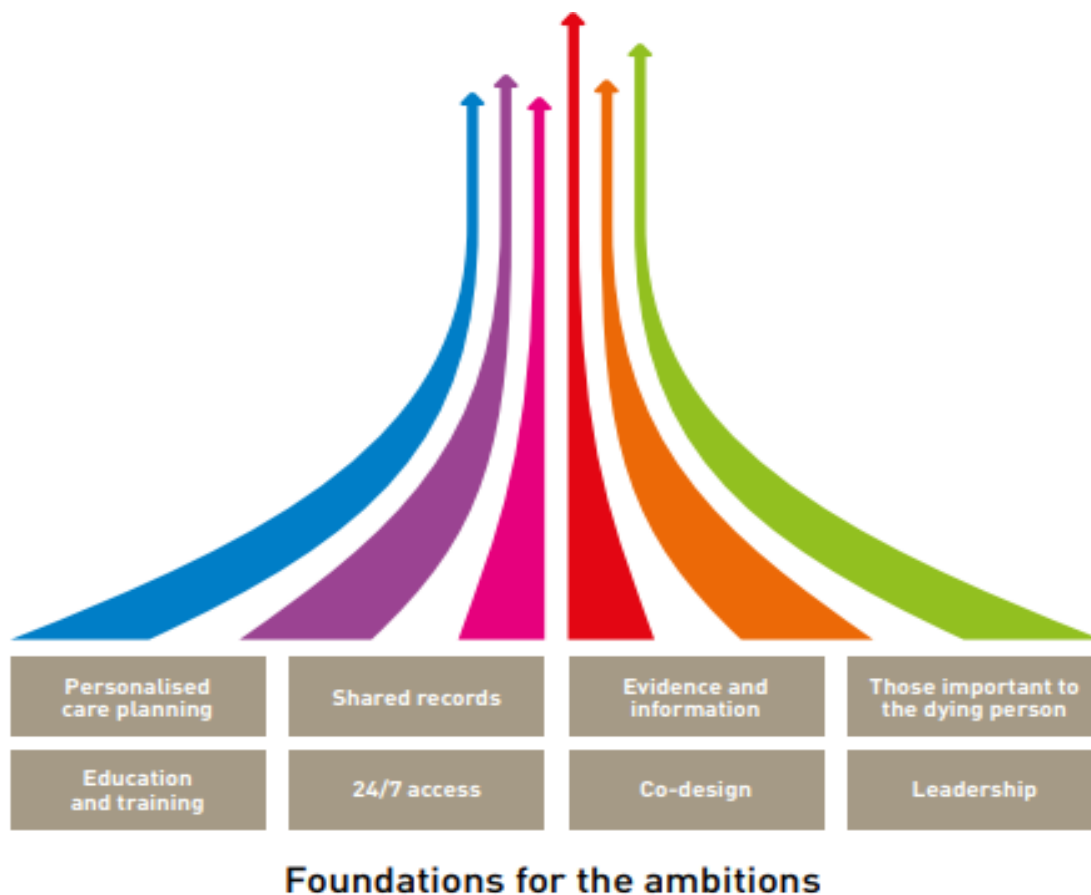
It describes what is needed to realise that ambitions, and calls for local health and social care leaders to use these foundations and building blocks to collaboratively build the accessible, responsive, effective, and personal care needed, via a process that is open, transparent and effective.

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.



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 Hammersmith & Fulham Council, HAFSON 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:

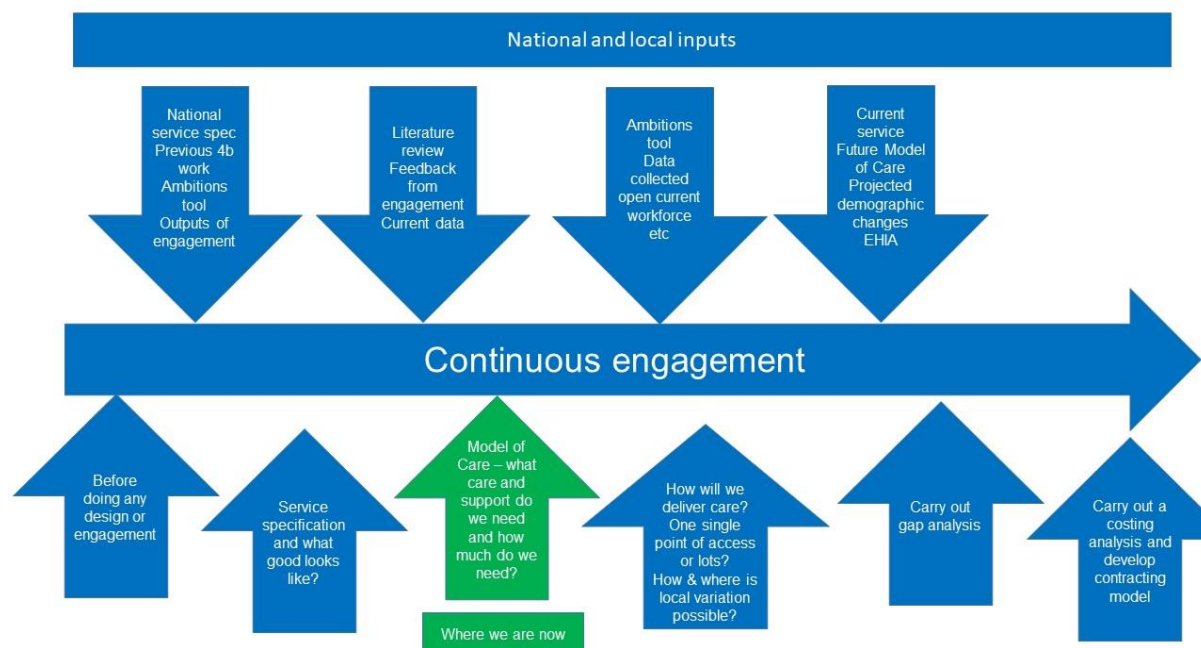
- Key gaps/ areas of improvement identified for other parts of the end of life pathway will be shared with other NW London programme areas.
- BBP self-assessments will be shared with BBP and borough directors with an ask to support any local PEOLC improvements using the findings to inform this work.
- 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.

10. Timeline

We are taking a flexible approach to the timeline to make sure that we can carry out meaningful 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.

11. 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.
- 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.
- 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 Hammersmith & Fulham Council. Please let us know by emailing nhsnw/ccg.endoflife@nhs.net